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“Certain Circumstances”

Issues in Equity and Responsiveness
in Access to Health Care in Canada

*A collection of papers and reports
prepared for Health Canada*

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"Certain Circumstances"

*Equity in and Responsiveness of the Health Care System
to the Needs of Minority and Marginalized Populations*

A collection of papers and reports prepared for Health Canada

2001

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Foreword

*Accessibility is among the five principles that are fundamental to Canada's health care system, as described in the *Canada Health Act*.*

But what is accessibility? What is reasonable access? And when we say "health care services", what services are meant? Traditional medical care alone, or care from health professionals other than physicians?

What groups of Canadians are not having their health care needs met? How best to try to serve them? What changes are necessary to health care policy, the delivery of health care services and the training of health professionals?

These and many other questions are explored by the authors of several papers prepared for the Health Care System Division of the Health Policy and Communications Branch of Health Canada, and by the participants of seminars and workshops sponsored by Health Canada.

The fact is that while Canada ranks among the top nations in the world in terms of the standards of health, this high standard is not shared equally by all sectors of Canadian society.

The use of health services in Canada is not generally affected by financial barriers such as income. "Nevertheless," wrote the Federal, Provincial and Territorial Committee on Population Health in its second report on the health of Canadians, "there appear to be persistent language and cultural barriers to the provision and/or the utilization of services in certain circumstances."

Health services—and the barriers to access of these services—function as determinants of health. When health systems fail to provide equitable care, or equitable access to care, they may worsen social disparities and be a factor in lowered health status.

In 1999, the Health Care System Division of Health Canada undertook an exploration of the issue of equity and responsiveness in terms of access to health care services in Canada. Abridged versions of papers and summary reports of seminars or workshops to date are presented in this publication, and a summary of the recommendations made to date follow.

This is but a beginning, however, much research and discussion are needed in the months ahead.

Ottawa, September 2001

Part I Equity in Access to Health Care

Document 1

Access to Health Services for Underserved Populations in Canada

Prepared by: Sarah Bowen, Consultant, B.A., M.Sc.

September 2000

Document 2

Removing Barriers II – Keeping Canadian Values in Health Care

Excerpted from the report edited by Ralph Masi, MD

May 2000

Access to Health Services for Underserved Populations in Canada

Prepared for:
Health Care System Division, Health Policy and Communications Branch
Health Canada, Ottawa, Canada

Adapted from the original, prepared by:
Sarah Bowen, B.A., M.Sc.

September 2000

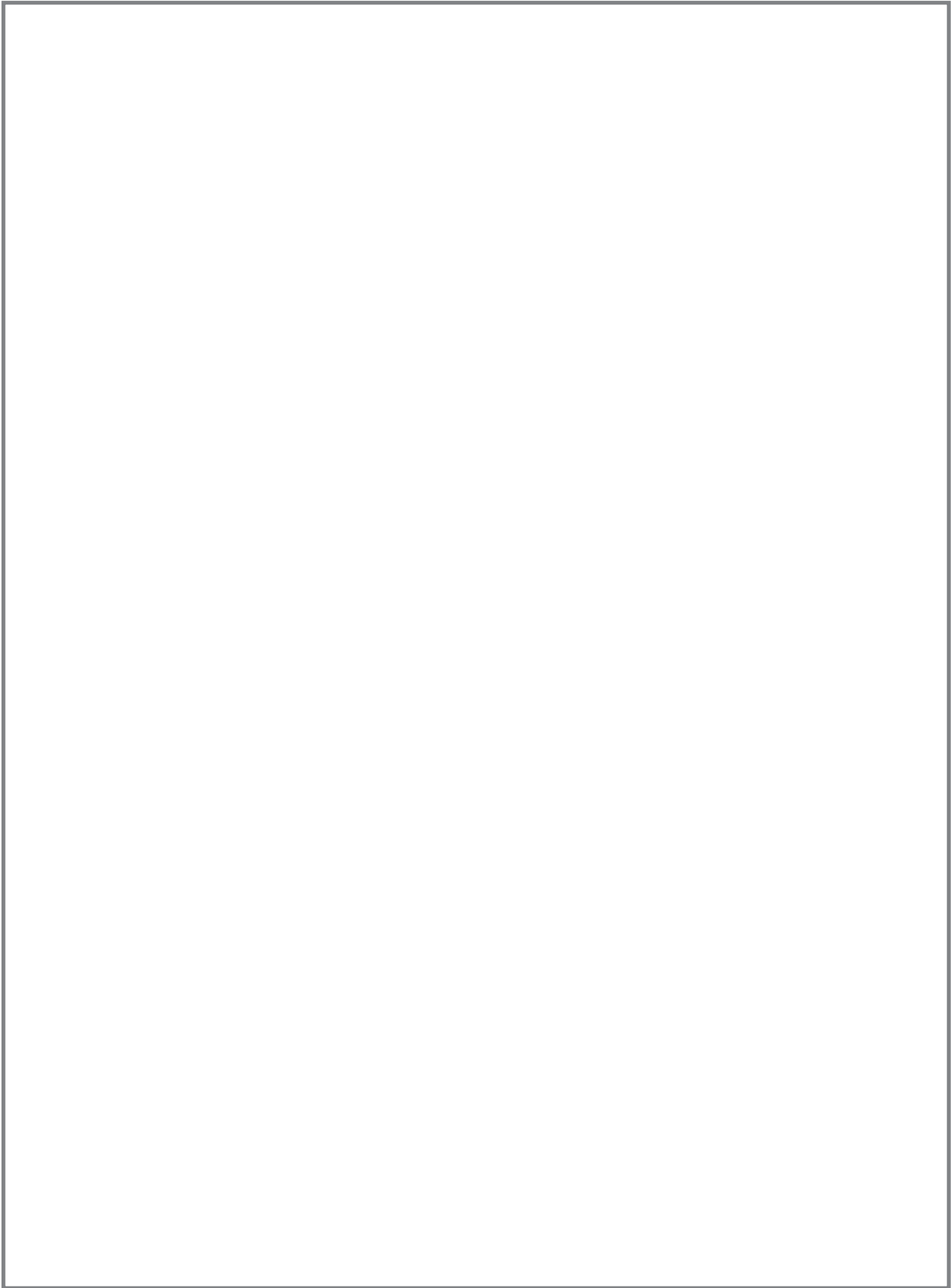


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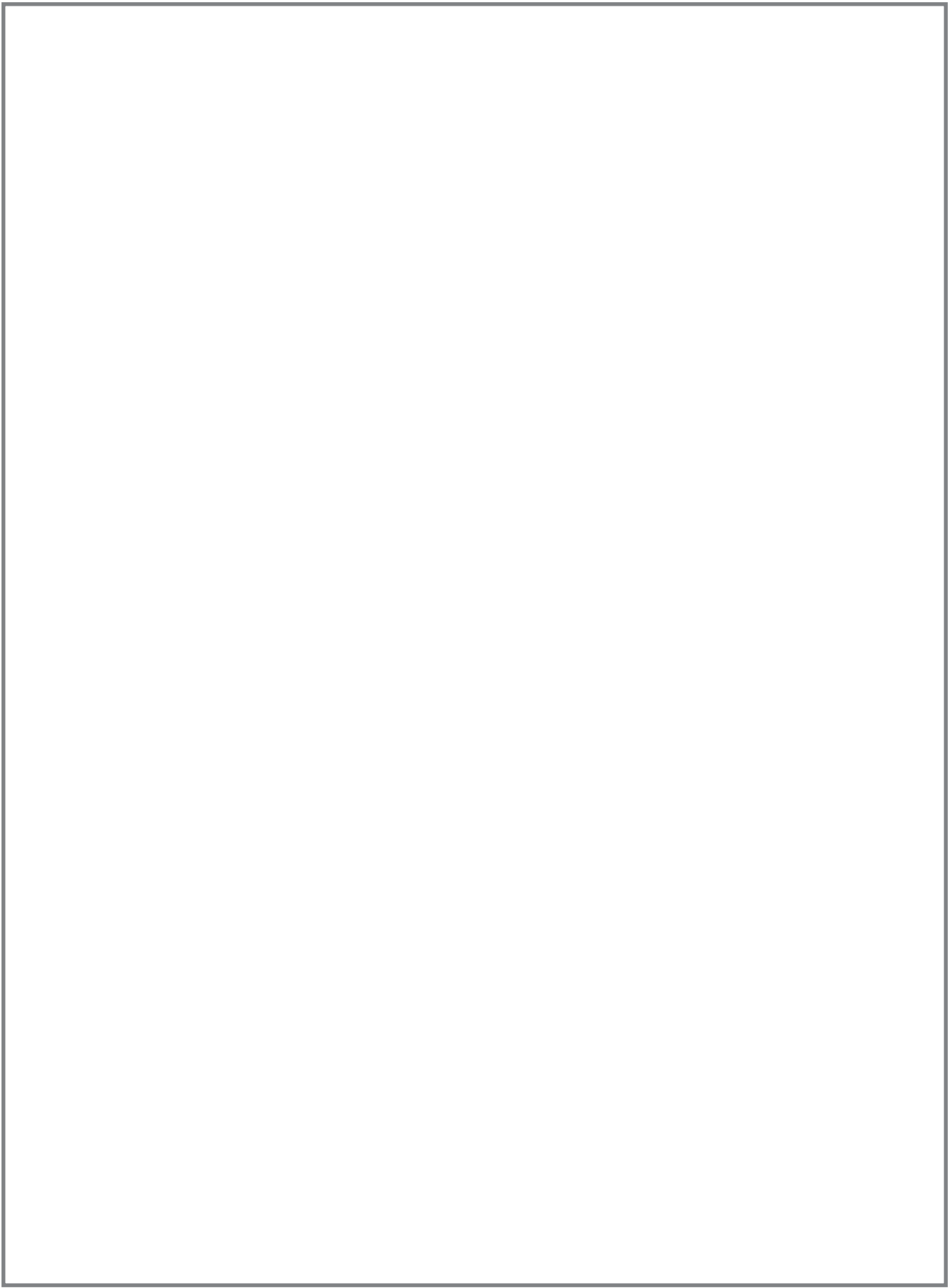
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Executive Summary

In 1984 Canada passed the *Canada Health Act* which stated the “primary objective of Canadian Health Policy is to protect, promote, and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers.” As a nation, Canada is committed to both health promotion and protection.

Today, Canada ranks well above most other countries in the world in most measures of population health. Canada’s system of universal health insurance has overcome financial barriers to access to health care for all citizens. Nevertheless, there are persistent and troubling, inequities in health status. Aboriginal people suffer from chronic diseases such as diabetes more than the general population; infant mortality rates are twice as high among First Nations communities; and Canadians with low literacy skills are more likely to suffer poor health. Immigrants and refugees encounter difficulties in accessing health services as do marginalized groups such as the poor and homeless.

To date, the focus of health policy and research in Canada has been on the removal of financial barriers to access, while other barriers to care have not been well explored. There is evidence of different patterns of health care use by certain populations and recognition that these populations face other, non-financial, barriers.

The underserved populations include Aboriginal people, people who do not speak either of Canada’s official languages, people with alternate sexual orientation, immigrants, refugees, ethnically or racially diverse populations, people with disabilities, the homeless, sex trade workers, and people with low incomes.

The term “reasonable access” from the *Canada Health Act* has not been defined, and there is continuing debate about what services are “medically necessary”. Factors such as language or cultural barriers or the inappropriateness of services are recognized as contributing to barriers to access to health care, but have not been subject to a comprehensive examination. Health care service utilization has been used as a measure of access, but this may be problematic in that differences in use may or may not indicate

equitable access. The data does, however, show disparities in the use of preventive and screening programs by underserved groups. These disparities indicate that some barriers affect the access to health not simply to health services.

This paper is a review of research related to health service access for underserved groups. A major objective of the report is to propose a framework for describing, categorizing and analyzing the evidence related to underservice of various populations in Canada, with a view to providing a structure for addressing further research needs. The paper focuses on the effect of factors other than income.

The Underserved

While it is acknowledged that certain populations in Canada are underserved, there is no consensus as to what this means. Three concepts are integral to the discussion of service provision to underserved groups: underservice, equity and access.

Underservice, in this paper, means there is an increased likelihood that individuals who belong to a certain population (and people can belong to more than one) may experience difficulties in obtaining needed care, receive less care or a lower standard of care, experience different treatment by health care providers, receive treatment that does not adequately meet their needs, or that they will be less satisfied with health care services than the general population.

An underserved population differs from an underserved region. The issue of service provision for underserved areas is largely one of supply and distribution of service and personnel, while the issues of underserved populations pertain more to access.

Equity in health means the fair and just distribution of resources. Not everyone receives the same service, or the same number of services, but the service provided is based on need.

Access is more than the availability of services; access assumes that services are provided in a way that is responsive to the needs of the health care system users, and is open to participation in

the planning of those services by underserved groups.

Barriers to access can be described in four categories: availability of services, financial barriers, non-financial barriers to presentation of health care needs, and barriers to equitable treatment.

The First Nations and Aboriginal peoples face serious problems. First Nations communities have problems related to availability of some services such as home care or mental health services, however, they may face fewer financial barriers to non-insured services because they are eligible to benefits through the First Nations and Inuit Health Branch. Aboriginal people living off-reserve have the same availability of services as other Canadians but face significant barriers to presentation of need for health care services as well as equitable treatment.

Immigrant populations demonstrate diversity in both health status and access issues. Often, health issues for immigrant and visible minority populations are combined, though different factors may affect access. Generally, newcomers to Canada do not face difficulties with availability of services, but they do encounter barriers to presentation of need. Immigrants may not be familiar with the Canadian system and may not understand what their rights to service are, what the roles of providers are, or what expectations of them are. For many, this gap is exacerbated by a lack of fluency in either English or French. Immigrants have also been shown to underuse preventive services and may be at risk for misdiagnosis and inappropriate treatment. Refugees have another set of special needs. Both immigrant and visible minority clients may face barriers to equitable treatment.

Four populations face barriers due to language: Aboriginal people, immigrants, people who use visual or sign language, and, depending on the location of residence, people who do not speak one of Canada's official languages. Historically, research has focused on general definitions of ethnicity, rather than the specific issue of ability to communicate in the language of the service providers. There is evidence that language itself, not ethnicity or socio-economic factors, may explain many differences in service utilization and health outcomes. Low literacy has been linked to lower health status and differences in access and utilization.

People of alternate sexual orientation come from all sectors of society and, as a group, are not at any greater risk for decreased health status due to socio-economic factors. Nevertheless, their health needs and concerns may differ from those of the heterosexual population. For example, the "coming out" process has been identified as critical for which support is rarely available. The health system has played a role in pathologizing alternate sexual orientation. Research indicates that some individuals may hesitate to seek health care, fearing negative reactions to disclosure; confidentiality is also a key concern.

Persons with disabilities come from all ethnic and cultural groups and they also face diverse barriers to access depending on the type of disability. Physical barriers may prevent the disabled from presenting for care, and a combination of socio-economic factors may present financial barriers. The attitudes of providers often present the greatest barriers.

Populations that are marginalized include the homeless, the mentally ill, street youth, injection drug users and sex trade workers. While these groups have diverse needs, they share similar issues in relation to access to care. Many have multiple risk factors. The homeless, for example, have problems with availability of services; many have no identification or a provincial health plan card, so are unable to access services to which they are entitled.

In spite of the variation in health status and the types of barriers experienced by the various underserved groups, there is a remarkable similarity in many of the concerns identified. Those who belong to more than one underserved group—for example, someone who is poor and female and living in an isolated area—may be described as facing a greater degree of difficulty.

Potential Responses for Improving Access for Underserved Populations

A number of different responses are required to address barriers to care for underserved populations. These responses can be described under three headings: Recruitment and Training, Program Design and Delivery, and, Policy and Structure.

Recruitment includes both preservice and post-training initiatives. There are a number of programs that facilitate access to professional training for members of underserved groups. This

strategy is of particular importance for Aboriginal communities. One example of a post-training initiative is the licensing of international medical graduates (IMGs). However, this has been a difficult and controversial area, and this response, in isolation, is not anticipated to have a significant impact on access needs.

Recent studies have indicated that while a number of initiatives to address needs for cultural competence training for health professionals have been introduced, more attention to promoting social accountability of medical schools is required. This is one area that has the potential to improve access for a number of underserved groups. The development of alternate health roles is another strategy that has potential both to address access needs, and to facilitate the participation of members of underserved communities in the health care system.

Academic health centres and other educational institutions play an important role in educating health professionals. There is a potential for a greater role in promotion of diversity training, development of training of alternate health professionals, and promoting research with underserved communities. They could also be given more responsibility for service provision to underserved groups.

Program Design and Delivery initiatives include “linking” programs, population-specific health programs, and telemedicine applications. Linking programs include health interpretation and, community outreach and education programs. Interpretation programs are essential to ensure access to health care for language minorities, however few health jurisdictions have implemented policy requiring professional interpretation services. Community outreach and education programs have an important role in addressing barriers to initial access and in ensuring quality of care. However, they may not address underlying organizational barriers to access. Another response is provision of population specific services. Several innovative programs focusing on Aboriginal people, persons with disabilities, immigrants, or homeless and low-income populations have been developed.

Telemedicine applications show promise in addressing access issues for rural and remote locations. First Nations communities are among those who may experience the most benefit. The

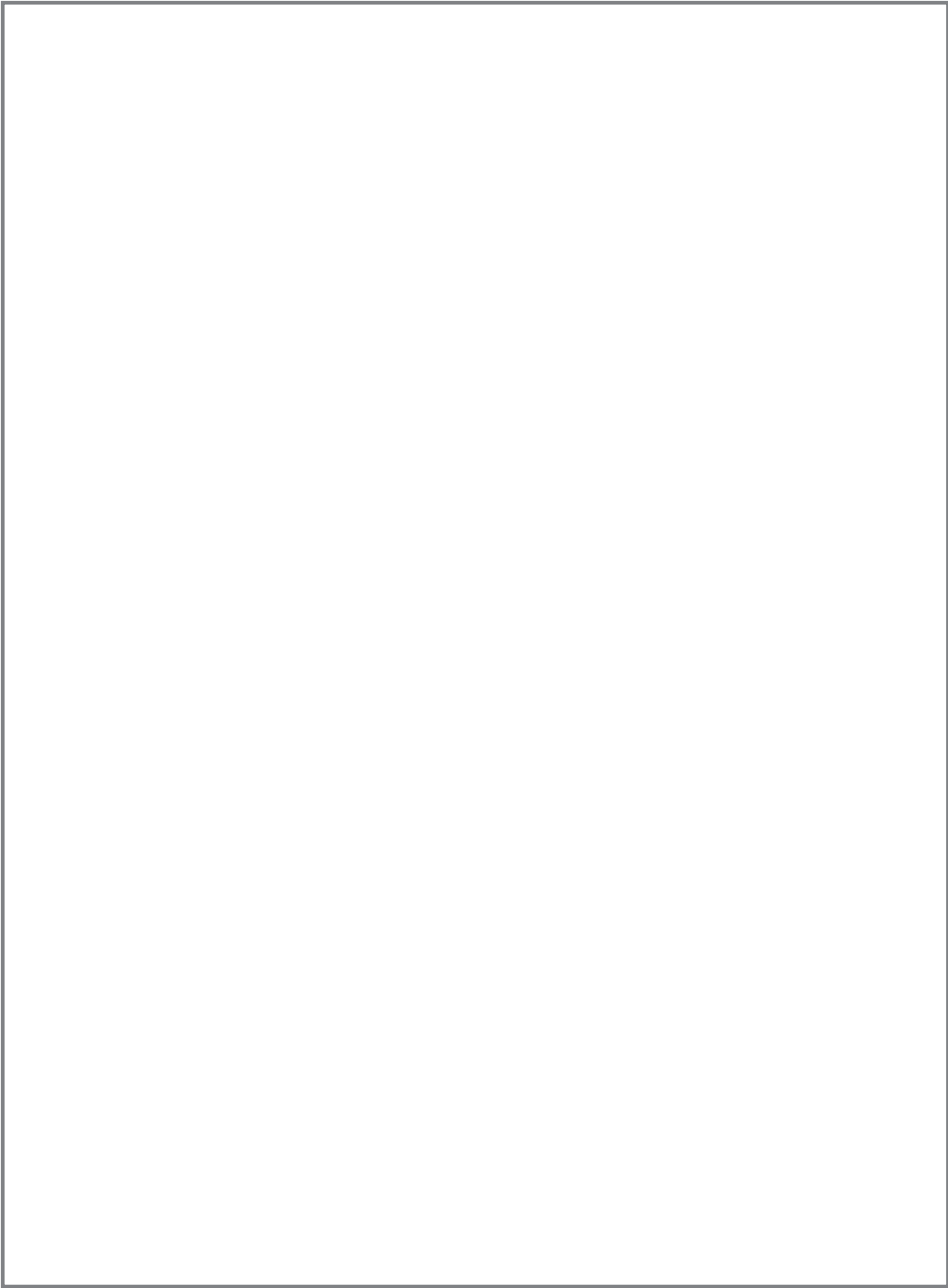
National First Nations Telehealth Project is evaluating implementation of a number of telehealth projects now underway. Research related to telemedicine applications indicates good results for both diagnostic accuracy and patient/provider acceptance. However, few studies have addressed issues of cost effectiveness. The potential for telemedicine to address linguistic or cultural barriers or support persons with disabilities has not been well explored.

Issues related to funding and provider payment models have a significant impact on underserved communities. The fee-for-service system has been of limited effectiveness in ensuring population coverage of preventive and screening programs; an area of identified concern for many underserved populations. Community health centres have often demonstrated greater ability to provide service to underserved populations. This is due both to their commitment to community accountability and to greater flexibility in hiring and program design. However, capitation payment systems may present additional access problems for underserved communities unless safeguards are built into the system.

Barriers to organizational access, (the degree to which consumers are represented and participate in planning, research and administration) must be addressed. This includes development of policy related to cultural diversification, flexibility of program delivery models, and implementation of strategies to ensure the participation of underserved communities at the decision-making level.

In spite of the diversity of barriers experienced by underserved populations, many of the responses that are recommended to address these barriers are similar. Many of the strategies are anticipated to result in improved service provision for the general population and have already been identified as priorities through the health reform process.

Rapid changes in the health care delivery system risk creating additional difficulties in access to equitable care for underserved populations. Attention to access issues faced by underserved communities is therefore of particular importance at this time.



Section 1: Introduction

The intent of this paper is to provide an overview and analysis of the issue of access to, and provision of, health services for underserved populations in Canada. For the purposes of this paper, “underserved populations” are understood to include Aboriginal people, official language minorities, those of alternative sexual orientations (gay, lesbian, bisexual, two-spirited, transgendered, and transsexual) immigrants, refugees, ethnically or racially diverse populations, persons with disabilities, the homeless, sex trade workers, and low income segments of the population.^a

Background

Canada ranks well above other countries in most measures of population health. Canada’s system of universal health insurance, considered one of the best in the world, has largely addressed financial barriers to access to health care for all citizens. However, persistent and troubling inequities in health status remain (Federal, Provincial and Territorial Advisory Committee on Population Health, 1999). There is also evidence of different patterns of health care use by certain populations and non-financial barriers to access for certain underserved groups.

It is recognized that many factors influence health. These “determinants” of health include living and working conditions, the physical environment, health services, early childhood development, social support, personal health practices and coping skills, and biology and genetic endowment (Federal, Provincial and Territorial Advisory Committee on Population Health, 1994). However, in addition to these factors, gender, culture, and membership in specific population groups also have significant effects on health status (Federal, Provincial and Territorial Advisory Committee on Population Health, 1999).

Understanding the determinants of health has helped explain why certain groups of people are healthier than others, and how the social and economic environment affects health. Initially, this

directed attention to the relationship between income and health status, and income and health service utilization. Research on these topics has confirmed that in Canada, use of health services is not related to a person’s income (Federal, Provincial and Territorial Advisory Committee on Population Health, 1999).

More recently, we have come to understand that some populations experience more negative effects on their health due not only to lower economic status but also to social factors such as racism, loss of social status and social isolation. These psycho-social factors can exert a powerful influence on physical and mental health, likely a greater effect than material poverty alone. Societies with the greatest disparities have lower health status than societies of similar wealth but where disparities are less (Wilkinson, 1996; Lavis and Stoddart, 1999). This situation spurs us to investigate further the effect of these psycho-social factors on health and the impact of factors other than explicit financial barriers which may affect access to health services.

The purpose of a population health approach is to maintain and improve the health status of the population as a whole, reducing inequities in health status between groups. Reducing inequities in health status will be one the greatest challenges to achieving population health (Federal, Provincial and Territorial Advisory Committee on Population Health, 1999). The recognition of the importance of societal factors in contributing to health and illness has increased awareness that there are limitations to the ability of health care to achieve a healthy population. However, there will always be a need for health services, both to treat the sick and injured, and to provide information and services which prevent disease and promote health. Health services themselves (and access barriers to them) function as important determinants of health. Health systems that fail to provide equitable care have the potential to exacerbate social disparities and contribute to lower health status. To date, the focus of health policy and research in Canada has been the

^a Underserved populations should be differentiated from “underserved areas”. Underserved areas are geographic regions, usually rural and remote, that experience difficulty in recruiting and retaining sufficient numbers of health personnel to meet the needs of the population, or are undersupplied with certain health services. The concept of “underserved populations” in contrast refers to those populations who, due to a variety of factors, may not have the same access to health services even though there may be “sufficient” resources in the geographic community where they live.

removal of financial barriers to access; other barriers to care have not been well explored.

Scope and Limitations of the Report

This review identified a paucity of published research related to health service access for underserved groups, and a lack of clarity of concepts related to the topic. A major objective of this report will therefore be to propose a framework for describing, categorizing, and analyzing the evidence related to underservice of various populations in Canada, with a view to providing a structure for addressing further research needs.

While recognizing the importance of research related to income and health service access, the paper will focus on the effect of factors *other than income*. The issue of workforce supply for rural and remote regions is the topic of a companion report and will not be addressed here. However, geographic barriers are not separate and distinct from other barriers to access, but inter-related. Those from underserved populations who happen to live in underserved geographic regions will likely face greater difficulties than those who live in better resourced regions (Ryan et al., 2000; Baker, 1993). The discussion will not be limited to provision of physician and hospital services, but will include other primary care and disease prevention/health promotion activities. Many of these programs and services, necessary components of a comprehensive population health approach, are provided by other health care professionals, or fall outside of the formal health care system.

The literature review draws on a number of sources. Key summary documents (Federal, Provincial and Territorial Advisory Committee on Population Health, 1999; Health Canada, 1999; Kinnon, 1999; Ryan et al., 2000) were important in developing the overview of health status and needs. Also included in the scan was an Internet

search of government documents, university research centre publications, key organizations, and reports and abstracts from Metropolis and the Women's Health Centres of Excellence. A data base search through Medline and Healthstar was undertaken, focusing on Canadian research related to Health Services Accessibility. This was supplemented by an expanded search related to key concepts, specific underserved groups, and identified barriers, and by a review of the bibliographies of key resources identified through the initial scan.

Time constraints, and the number of different populations and domains of interest, did not allow for a search of additional databases, the opportunity to follow up on all resources, or to contact organizations or researchers directly. As the review found that much of the information on access barriers from the community perspective is found in the "grey" rather than the published literature, many more resources may be available than were identified through this initial scan. The number of populations addressed also limits the ability of this report to capture the complexity of the access issues facing each population, or the interaction between various types of underservice and issues such as gender, income, or place of residence.

The next section will provide a brief discussion of the context of provision of health services in Canada, particularly as it relates to the issues of supply and access, and will further discuss terms and concepts related to access to health care. Section 3 provides an overview of general research issues and methodological limitations related to research on non-financial barriers to access. Section 4 summarizes what is known about various types of underservice in Canada for a number of underserved populations. Finally, in Section 5, potential responses to issues of underservice are reviewed.

Section 2: Context and Concepts

Context of Health Service Provision

Any health care system is an outgrowth of the political culture, the social and moral values and the economic imperatives of the society it services. One cannot make neat distinctions between the legal, ethical, clinical, political and economic factors which all play a role in shaping the country's health care system. (Canadian Bar Association Task Force on Health Care, 1994:1).

Canada's system of universal health insurance grew out of a commitment to removing financial barriers to health care for all Canadians. The ongoing development of this system, and delivery of services, take place within a political system where responsibility for most health services falls under provincial/territorial jurisdiction, but is supported by the federal government, and directed by the principles of the *Canada Health Act* (CHA).

Canada provides universal medical coverage to all its citizens under the terms of the *Canada Health Act* (1984). The *Canada Health Act* is based on five principles: *universality, portability, accessibility, comprehensiveness, and public administration*. It states that the "primary objective of Canadian Health Policy is to protect, promote, and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers". As a nation Canada is therefore committed both to health promotion and protection (keeping people healthy), and to restoring well-being (treating them when they are not healthy).

However, because access is not defined, it is not clear what would be required to show access was *reasonable*. Most often access has been defined simply as the absence of explicit financial barriers. *Universality* requires that 100% of the residents of a province be entitled to insured services on uniform terms and conditions. *Comprehensiveness* is the requirement that the health insurance plan of a province cover all "insured health services provided by hospitals, medical practitioners or dentists, and where the law of a province so permits, similar or additional services rendered by other health care practitioners." All services "medically necessary for the purpose of maintaining health, preventing disease or

diagnosing or treating injury, illness or disability" are included; however, there has been continuing debate about what services are "medically necessary".

"Extended health services", which include home care, nursing home and adult residential care, and ambulatory care service are also included in the Act. However, provinces are not required to provide these services, and some payment for accommodation in residential facilities may be required. At present, availability and coverage of extended health services varies markedly between provinces and territories.

At the time the language of the original legislation was developed (the *Canada Health Act* was based on two earlier pieces of legislation, the 1957 *Hospital Insurance and Diagnostic Services Act* and the 1966 *Medical Care Act*), it was expected that most care would be delivered in hospitals and by physicians. The restriction of insured services to "medically necessary services" provided by hospitals and physicians has skewed subsequent patterns of service delivery in Canada. It has reinforced the position of acute care and institutional services at the expense of community and preventive services, and defined care by who provides it, and where it takes place, rather than whether care is needed (Hurley et al., 1996). While a population health approach results in a focus on providing services in the community and treating sick people at home, this trend has the effect of "off-loading" expenses from the publicly funded system to third party payers or to individuals. Inequities in provision of non-insured services, which include dental services, vision correction, prescription drugs and counselling or mental health services, have been highlighted as an area of growing concern (Federal, Provincial and Territorial Advisory Committee on Population Health, 1999). Canadians who do not have supplementary insurance coverage (through employee plans or social assistance programs, for example) may not be able to afford some services. Some services, such as health outreach or education programs provided outside of the formal health system, are not insured services and so do not fall under the scope of the Act. These initiatives form a crucial component of a comprehensive system that addresses the need to promote and protect, as well as restore, health.

Provincial/Federal Authority

The “Canadian Health System” is not a federal health system; rather, it is a collection of provincial systems. Provinces and territories are responsible for the planning, administration and delivery of health services. However, there is a national plan in that all provincial and territorial plans are linked through adherence to national principles set at a federal level. Provincial and territorial plans must meet certain criteria to qualify for full transfer payments from the federal government. The federal government also retains responsibility for certain populations and health services; two of these are health care to registered First Nations and Inuit people, and to refugee claimants.

Provision of Health Care to Aboriginal People in Canada

The term Aboriginal describes all indigenous peoples of Canada, and includes First Nations peoples (previously referred to as Indians) registered under the *Indian Act* (Registered Indians), North American Indians not registered under the *Indian Act*, Inuit and Metis. Aboriginal persons are covered for hospital and medical costs by provincial health insurance plans in the same way as other Canadians. However, registered Indians and Inuit (who are not divided into status or non-status categories) are also eligible for health programs administered by the First Nations and Inuit Health Branch of Health Canada.

Relative responsibilities of the federal and provincial governments are poorly defined. Shared responsibility has been the source of confusion and ongoing debate since the *British North America Act* defined health care as a provincial responsibility and “general care of Indians” as a federal responsibility. Historically, the federal government has had a special responsibility for health care for Aboriginal people. In 1979, the Indian Health Policy established a framework for delivery of Indian and Inuit health programs. This policy acknowledged the “special relationship of Indian people to the federal government” and recognized the importance of socio-economic, cultural and spiritual development in addressing underlying causes of poor health.

The federal government and Aboriginal peoples disagree on health care as a treaty right. The position of the Assembly of First Nations (AFN) is that health is a treaty right, and an element of First Nations’ inherent right to self-government. The AFN also maintains that provision of health services is an area of undefined federal fiduciary obligation. The federal government has agreed to provide health care to First Nations and Inuit people where this would not otherwise be available, which excludes off-reserve Aboriginal peoples from federal health services and programs. Additional services through Health Canada are provided through the First Nations and Inuit Health Branch, and are available only to Registered Aboriginals (not to non-registered Aboriginals or Metis). This has led to disparity in the type and extent of coverage of Aboriginal persons by status.

In 1986, the Health Transfer Program was initiated; the intent was to transfer control of federal Indian health services to First Nations people themselves. Transfer is to occur within the existing legal framework and funding base. As of March 1998, 74% of First Nations communities were involved at some level in the process of transfer, with 31% of these having signed transfer agreements (Health Canada, 1999). The health transfer process places the discussion of health services for First Nations peoples within a different context from that of other communities, and has important implications for the issue of access to health care.

Refugee Claimants

Prior to 1994, refugee claimants^b to Canada were not eligible for health care coverage, although some provinces had made some arrangements for care. The Interim Federal Health Program, administered by Citizenship and Immigration Canada, is intended to ensure emergency and essential health services for needy refugee claimants and those refugees in Canada who are not yet covered by provincial health plans.

Rights to Access

In the discussion of access to health care by underserved populations, the human rights legislation of a country must also be considered. In Canada there have been few challenges to

^b A refugee claimant is a person who has arrived in Canada and seeks convention refugee status (Citizenship and Immigration Canada). It is important to differentiate between *refugee claimants* and *refugees* who are accepted as landed immigrants in Canada and are eligible for health coverage under the same conditions as other immigrants.

interpretation of *access* as simply the absence of explicit financial barriers to health care. Claims involving rights of access to health care are principally based on interpretations of the Canadian Charter of Rights and Freedoms, the *Canadian Human Rights Act*, provincial human rights acts, and the *Canada Health Act*. A recent ruling by the Supreme Court of Canada found that absence of communication resulted in substandard care and determined that hospitals were required to provide interpreters for deaf patients (*Eldridge v. British Columbia [Attorney General]*, 1997). There are also requirements that facilities be physically accessible to persons with disabilities.

Cultural Context

The establishment of Canada's system of universal health insurance was part of a larger commitment to social welfare programs. These programs grew out of a philosophy of mutual aid and a willingness to protect the less fortunate. The health system not only removes financial barriers, but also becomes part of the environment of social support.

"Underserved populations" in Canada are a number of different constituencies which experience a range of potential problems with access. They may be served by different organizations and government departments, and may have different rights to access under the law. Even where issues of concern may be similar (e.g. discrimination or language access to health services) there may not be joint action, or consensus on the best solutions by the different constituencies. While the discussion of Aboriginal health services takes place within the context of the right to self determination of First Nations peoples, the issues facing immigrants and refugees are often seen as "newcomer" issues that will resolve with time. Similarly, issues of access of gay, lesbian and bisexual persons, or of persons with disabilities are also often seen as "separate" issues, and of concern to different stakeholders.

The Impact of Health Reform

Canada's health system, like that of most countries, has undergone significant restructuring over the past several years, mainly in response to concerns about escalating health care costs. Actions taken to contain costs have resulted in concerns about equity, concerns that resource allocations should be made consistent with the

needs of populations, and concerns that inequitable distribution of health care resources is resulting in geographically remote and socially disadvantaged groups having less access to appropriate care.

Many provinces have undertaken commissions to review health care systems. A number of recurring themes have emerged from such reviews. These include: broadening the definition of health; shifting the emphasis from curing illness to health promotion and disease prevention and from institutional to community care; increasing opportunities for participation of consumers; regionalization; improved human resource planning (with an emphasis on alternative remuneration for physicians); increased coordination of services; increased funding for health services research; and evidence based decision making (Mhartre and Debber, 1992; Hutchinson and Abelson, 1996; Closson and Catt, 1996).

Responding to these issues may improve service to underserved populations, but the issue of access has not been addressed. Issues of concern to diverse and disadvantaged groups may in fact be lost in the restructuring process. For example, regionalization, (the devolution of care to smaller health authorities), has been proposed as a potential benefit to vulnerable populations. By moving decision making closer to the health care user, in theory, services should become more responsive to local needs. However, there are several challenges.

- ◆ Underserved populations have not traditionally been adequately represented in decision making structures.
- ◆ Data collection systems do not collect data in a way which assists in identifying or measuring needs of underserved groups.
- ◆ There is an inadequate research base on non-financial access barriers, or needs of underserved groups, resulting in neglect of these issues in planning.
- ◆ Traditional funding patterns have resulted in "access" services being excluded from core funding.
- ◆ A cost containment emphasis results in reluctance to identify need for additional programs.
- ◆ Effects of health care restructuring have focused public concern and planning responses on what are perceived to be more

pressing issues (e.g., waiting lists, hospital closures).

A major emphasis in health reform has been to ensure that health care costs can be maintained at sustainable levels. Adoption of a population health approach has focused attention to the need to shift the emphasis within current services towards prevention, shift funding within the system to more “upstream” services, and to address the underlying causes of ill health. In reality, however, many community-based programs focusing on disease prevention and health promotion have experienced the same financial cutbacks as acute care services. These programs, which provide services such as health interpretation or preventive health education, play a leading role in facilitating access for underserved groups.

It is not clear how emerging concerns about general health access (waiting lists, private clinics, early hospital discharge, or access to home care services) may affect populations who are already considered underserved. However, because membership in many such groups is correlated with lower economic status (and/or lower levels of social support), it is to be expected that these populations may bear a disproportionate burden of any decreased availability of service.

Defining Access and Underservice

While there is widespread recognition that certain populations within Canadian society are underserved, there is no consensus on what this means. Three concepts that are integral to the discussion of service provision to underserved groups are “underservice”, “equity” and “access”.

Defining Underservice

Underservice is defined by various writers in different ways, and may be used to describe problems with service availability, service access, or the quality of treatment obtained. In this paper, underservice refers to an increased likelihood that individuals will, because of their membership in a certain population: experience difficulties in obtaining needed care; receive less, or a lower standard of care; experience differences in treatment by health personnel; receive treatment that does not adequately recognize their needs; or, be less satisfied with health care services.

Many underserved populations share the characteristics of lower income and social disadvantage. The evidence for the effect of these

determinants on health status has been the subject of extensive study and will not be the focus of discussion here. However, underserved populations cannot be defined by low income alone. Some underserved populations (e.g. the homeless) are not only poor, but of low social status. They may present with health conditions which are not as well managed by the formal health system (e.g. mental health disorders or substance use). They are at risk for decreased health status, and are likely to face non-financial barriers to health care access as well as discriminatory treatment within society as a whole and the health system. Members of other groups (such as visible minorities, gay, lesbian and bisexual) may face inequitable treatment by the health care system, even if they are not of low economic status. Not all members of underserved groups are poor or less educated, indicating the importance of other barriers that may be independent of socioeconomic factors.

A person may share characteristics with one or several groups defined as underserved. People of lower socioeconomic status and who are underserved for some other reason are further jeopardized. The provision of basic insured services in Canada does not appear related to income, but there are “persistent language and cultural barriers to the provision and/or the utilization of services in certain circumstances.” (Federal, Provincial and Territorial Advisory Committee on Population Health, 1999, p. 145) The interaction between these factors may present further barriers to equitable care.

Underserved Populations and Underserved Regions

Addressing inequities experienced by underserved populations is a fundamentally different issue than ensuring equitable distribution of the “same” resources across geographic regions. The issue of service provision for “underserved areas” is by and large an issue of supply and distribution of health personnel and services, while the issues facing underserved populations are more a problem of access. Underservice due to geographic location, and underservice due to membership in a specific population differ in a number of ways: the factors contributing to the problem of underservice, the actual problems of “access” which result, strategies for measuring need, the scope of effect of the access barriers, and potential solutions.

Defining Equity

Equity in health refers to the fair and just distribution of resources. The concept of equity differs from that of *equality*; the measure of health care equity is not that every one receives the same service, or the same number of services, but that the service provided is based on need. In Canada, equity is generally described as “equal access (or equal service) for equal need”. It is recognized that those who are sicker, or face greater risk to health, should receive a greater intensity of service, and it follows that lower income groups should receive more services. While care in Canada is related to need, not income, the question has been raised as to how much more care those of lower health status should receive compared to those in better health. Some writers have suggested that while more services are provided to those at the lowest income level, the differential does not necessarily correspond with observed differences in health status (Roos et al., 1999). More research is needed in this area.

Simply providing equal service for equal need may not be sufficient to achieve equity. This is best illustrated by example. If an institution is responsible for food service provision, equality is achieved if all consumers receive the same quantity and quality of food. However, if the menu is steak and some of the consumers are vegetarians, equal service is not equitable service, which most would agree would involve the provision of a quality vegetarian meal.

Defining Access

Access is another concept that has received various interpretations by policy makers, researchers, and the general public (Birch and Abelson, 1993). The Oxford dictionary defines accessibility as “capable of being used, entered or reached”, and as “open to the influence of”. This implies that access is more than the availability of services. It assumes provision of services in a way that is both responsive to the needs of users and open to the participation in planning of services by underserved groups.

“Barriers to access” can relate to *client access* (the degree to which individuals are able to secure needed services), and to *organizational access* (the extent to which consumers are represented and/or participate in the planning, development, delivery and administration of services (Doyle and Visano, 1987). With the exception of initiatives to

transfer control and administration of health services to First Nations communities, and the Independent Living movement, discussion on access for underserved populations tends to focus on issues of client, rather than organizational access.

In the literature, access is variously defined as “availability of service”, “use of health care by individuals with a need for care” (Waters, 2000), or “equal quality of care received”. In regard to distribution of physician and hospital services, *reasonable access* is generally understood to mean equal access for equal need, and the absence of explicit financial barriers. The focus on explicit financial barriers to care, and by extension, on utilization of care related to income status, has resulted in neglect of other potential factors, which may impair access. It has been observed that “lack of attention to other non-price factors that might be expected to influence the demand for and/or the supply of care appears to imply that service provision free at the point of delivery is a sufficient condition for “reasonable access” to services.” (Birch et al., 1996, p.6.) However, there has been increasing awareness that “accessibility” must be defined more broadly than this. For example, the Panel on Health Goals for Ontario (1987) stated:

“All residents of Ontario have the right to high quality, accessible, appropriate and comprehensive health services independent of age, gender, level of functional ability, language, ethnocultural origin or geographical location. . . . Accessibility should be understood to include psychological, social, emotional and economic aspects” (p. 87).

Historically, the focus has been on providing equal access to *treatment*; the adoption of a population health approach, however, means we need to look at the importance of barriers to *assessment* (Culyer, 1991). If barriers reduce the likelihood that certain populations can be assessed and receive an accurate diagnosis, then provision of treatment on an equitable basis once a need is identified is insufficient.

Physician and hospital services are the core insured services in Canada, and the focus of measures of access and equity. The most common focal point for delivery of health services in Canada is the family physician. These primary care physicians also function in the important role as “gatekeepers” to other health services including specialist and hospital care. The population health

approach suggests that while important, access to physicians or hospitals alone may not be an adequate measure of service access. Key preventive, continuing care, and education/support services are provided in the community and by other health professionals and organizations. Access to these services must also be considered in any comprehensive review of access.

Mooney et al. (1991) observe that in Canada, it is not clear whether the objective of equity relates to *utilization* or *access*. There is confusion then about whether equity is defined by receipt of care, or by opportunity to utilize care (access). In the discussion of equity and access, it is important to consider that the purpose of health policy is not to provide health services but to achieve the best possible health of the population. The ultimate goal then is *access to health*, not simply access to health services.

Equitable access can then be defined as *provision of health services in a way that provides an equal opportunity for all citizens to achieve maximum health*. The following section outlines a framework for discussion of factors that may act as barriers to this goal.

A Framework for Describing Access and Access Barriers

This section provides a framework for categorizing the various types of difficulties experienced by underserved populations in accessing health care services. These difficulties (or barriers) can be described in the following categories: availability of services; financial barriers; non-financial barriers to presentation of need; and, equitable quality of care.

Availability of Services

One aspect of access is *availability of service*. Individuals may not have “access” because:

- ◆ a health service may be unavailable because it is not insured under medicare;
- ◆ a health service may be funded, but long waiting lists mean it is not available when needed;
- ◆ a service may not be available on an equitable basis due to geographic factors (provincial/territorial differences, or issues of rural/remote supply).

These three commonly used definitions of access are not the focus of this paper. No health system has the resources to provide an unlimited number of services, so services deemed as less necessary will be uninsured. “De-insuring” of services may not pose a challenge to equitable provision of services, as long as all are treated equally.

The issue of waiting lists for many medical procedures, (currently a common focus of the public discussion on access) may not result in *inequitable* access, as there is little evidence to date that members of “underserved populations” face longer waiting times than other patients. However, there is public recognition that “private” (i.e., fee-for-service) clinics to address waiting lists raises serious concerns about equitable access by introducing financial barriers to some insured services. Regional shortages of primary care physicians may also have an effect; research indicates that Canadians who do not have a regular family physician are less likely to receive primary or specialist care (Dunlop et al., 2000). If physician shortages have a disproportional effect on underserved populations, this would be considered an aspect of inequitable service.

While the significant problem of health service provision to rural and remote areas is not the focus of this paper; it is important to recognize that both income and membership in an underserved group, interact in direct and indirect ways with geographic barriers. This can place vulnerable groups at even greater disadvantage.

Financial Barriers

The second category of access barriers relates to explicit *financial barriers*. In other words,

- ◆ a service may be available, but there may be monetary costs associated with its use.

This category can be subdivided as follows: a) explicit financial barriers to insured health services, b) explicit financial barriers to uninsured services, and c) other financial costs associated with access.

There is increasing concern that universally insured services may be eroding. The growth of private clinics for some medical procedures in some provinces has also raised a high level of public concern that a two-tier level of medical care may be emerging. Clearly, people in lower income levels will have fewer options under this system; underserved populations are

disproportionately represented among lower socioeconomic groups.

While it is generally accepted that financial barriers to *insured* services have been removed in Canada, disparity is growing in access to *non-insured* services. Many Canadians with low or moderate incomes have limited or no access to health services such as eye care, dentistry, mental health counselling and prescription drugs (Federal, Provincial and Territorial Advisory Committee on Population Health, 1999).

Underserved groups may also face greater difficulties in meeting the indirect financial costs related to health care utilization. These costs include child care, transportation or unpaid time off work for medical appointments. Certain groups are more likely to face these barriers, and while it is not feasible to calculate such indirect costs of utilization, “accessible” services must address issues such as location and hours of operation.

Non-Financial Barriers to Presentation of Need

The focus on income-related barriers to access has resulted in relative neglect of non-financial barriers to care, including barriers that prevent patients from achieving first contact with health care services (and thus presenting for assessment). Barriers in this category can prevent equitable access even if providers are committed to providing equitable service upon presentation of need.

- ◆ A service may be available, but linguistic barriers, inaccessible facilities or other barriers may result in a patient being unable to present for care.
- ◆ Potential users may not be aware that a service is available, rights to service, or how to access the service (information barriers).
- ◆ Individuals may not request services because, even though they are aware of them, they are not aware of (or do not believe in) their importance (cultural or education barriers).
- ◆ Although services are available to all, practices related to delivery discourage utilization by certain populations.

This category of barriers has a significant impact on awareness of, and participation in, preventive and health promotion programs. Provision of preventive information is much broader in scope than that of physician care and includes information obtained through the media and

community events. Language and cultural barriers, as well as lower literacy, are correlated not only with decreased participation in preventive programs, but also with lack of awareness of risk, lifestyle interventions, warning signs, and benefits of screening. Barriers to presentation of need tend to lead to a situation where utilization of services may be “acute care driven”, rather than based on regular or preventive care.

Barriers to Equitable Treatment

Even if individuals present for care, they may encounter barriers to *equitable treatment*.

- ◆ Communication/cultural barriers may result in misdiagnosis/inappropriate treatment.
- ◆ Rights of confidentiality and informed consent may not be protected.
- ◆ Service utilization may be discouraged or refused for certain populations.
- ◆ Different treatment may be prescribed based on group membership.
- ◆ Provider-patient interaction may differ based on group membership.
- ◆ Policies may not recognize the needs of certain populations.
- ◆ Program design may result in the needs of some groups being better served than others.
- ◆ There may be less expertise related to health conditions of, or treatment efficacy for, some groups.

Each is a potentially serious barrier to equitable access to care. Communication is an essential component of health care. One of the most dramatic forms of communication barriers has been found in situations where patients cannot speak the same language as their health care providers. Without adequate communication there is an increased risk of “miscommunication, misdiagnosis, inappropriate treatment, reduced patient comprehension and compliance, clinical inefficiency, decreased provider and patient satisfaction, malpractice injury, and death.” (Office of Minority Health, 1999). Inadequate communication precludes the negotiation of informed consent and so results in risks to both patient and provider (Tang, 1999; Kaufert and Putsch, 1997; Stevens, 1993b). Cultural differences may also contribute to miscommunication.

It is also possible that members of underserved communities may be prescribed different treatment, depending on their membership in a specific population. Even if the technical level of care provided is “equal”, attitudes and behaviour demonstrated by providers may result in lower quality of care. Such barriers may be described by community members as “racism”, “ethnocentrism”, “homophobia”, or “ableism”; and by service providers as lack of “cultural competence”. The issue of trust in the provider/client relationship has been explored in detail (Kaufert and O’Neil, 1998), as have issues of communication (Stewart, 1995). Poor communication and low trust have been linked to decreased patient satisfaction, lower levels of compliance, subsequent patterns of health service utilization and treatment outcomes. Therefore, discrimination in any form can be expected to result in poorer health outcomes.

Policies may not address the needs of certain clients, or may create conditions that result in lower quality of care. Absence of appropriate policy can have the same impact as inappropriate policy. For example, failure to require professional interpreters results in lack of protection for patient rights to informed consent.

Two additional aspects of access are more complex and difficult to address: the way services are structured and the knowledge base on which assessment and treatment is based. The way services are structured and the priority given to various types of services reflects both the historical development of the health system and the beliefs and preferences of current administrators and policy makers. Members of underserved groups have historically been underrepresented in these areas, so services do not necessarily reflect their needs, interests or priorities. Barriers arising from these inherent characteristics of service provision (often referred to as “lack of appropriate services”) may result in programs and services not meeting the needs of certain populations. Such barriers can include such varied factors as:

- ◆ 9-5 office hours;
- ◆ an environment which is experienced as intimidating or insensitive;
- ◆ routine inclusion of practices which are not acceptable to the identified population ;
- ◆ physically inaccessible facilities;
- ◆ lack of expertise related to specific experiences, beliefs, needs or preferences;
- ◆ lack of interpretation services;
- ◆ failure to provide services which are an essential component of needed care from the clients perspective (e.g. areas for smudging ceremonies, culturally acceptable food).

It has also been documented that ethnic and language minorities have not been well represented in health research, ranging from population health surveys to clinical trials (Cotton, 1990; Frayne et al., 1996; Roberson, 1994; Anderson, 1993). While it is acknowledged that there may be significant differences between populations in risk of disease, prevalence of health conditions and response to treatment (Harrison, 1994; Seth et al., 1999), unless all populations are represented in research the knowledge base on which providers base treatment may not be complete.

As this framework indicates, there are a number of barriers to underserved populations receiving the care they require. Many individuals face barriers resulting from membership in more than one underserved population. Simply addressing the issue of poverty does not address all types of access barriers, namely geographic, linguistic, cultural, or barriers which result from prejudice or from discrimination against various groups, or their exclusion in the research and planning process.

Section 3: Quantifying Populations and Needs

Research Related to Access of Underserved Populations

Introduction

In order to understand the significance of any problems in distribution of needed services and of access to them, it is necessary to be able to determine:

- ◆ the size of the defined population at risk of impaired access;
- ◆ the health status of the defined population;
- ◆ the type and prevalence of difficulties in access experienced by this population.

The Metropolis Project (Health Canada, 1998), in the process of prioritizing research domains related to health, identified a number of specific research issues related to the question of access. While this project focuses on immigrants and health, these research questions apply as well to other populations:

- ◆ whether access to health services, of any kind, is less for immigrants (or underserved populations) than for native born (or the general population);
- ◆ if access is poorer, why this is so;
- ◆ what role racism or other forms of discrimination play;
- ◆ whether culturally sensitive services are more effective in producing positive health outcomes; and
- ◆ what the rights of immigrants (underserved groups) to service should be.

The initial review of the literature undertaken for this paper identified little research undertaken in Canada on these questions of access, although significantly more is known about the health status of various populations. A review of the literature in the Atlantic region reached a similar conclusion (Sharif et al., 2000).

A number of observations can be made from the initial review.

- ◆ There is consensus from community level consultations and community-based surveys that many populations are less well served by the health system. This is attributed to “language barriers”, “cultural barriers”, lack

of cultural sensitivity, or racism/discrimination.

- ◆ Little academic research has focused on issues of access, for any of the populations identified. The issue of access often emerges as a “byproduct” in the course of research on other topics (such as of health status) or is proposed as an explanation for various differences in utilization or health related behaviour.
- ◆ The concept of “access” is poorly defined. Academic research focusing on access often uses “utilization” as a measure of access. Limitations of this approach are discussed later in this section.
- ◆ The concept of “barriers” remains conceptually imprecise, and is often discussed in general terms such as “cultural barriers”.
- ◆ “Membership” in the underserved population to be studied is also poorly defined, which leads to difficulties in measuring populations.
- ◆ There are few linkages made between access issues faced by various “underserved populations”.
- ◆ The absence of well defined terms and concepts, and current limitations in data collection significantly limit the usefulness of population health surveys or existing databases for studying issues of access.

Lack of conceptual clarity and a limited body of existing research means it is difficult to determine what types of access barriers are experienced by various populations, how prevalent they are, or what the impact of these barriers is on access to health services.

Applicability of Research from Other Countries

In the absence of Canadian-based research, it is often useful to review research conducted in other countries. However, caution must be taken in generalizing this research to the Canadian context. For example, any research on access issues undertaken in countries without universal

health insurance will be affected by the fact that many of the respondents face financial barriers to health care. Even though racial/ethnic/cultural differences are observed when factors such as insurance coverage are controlled for (Mayberry et al., 1999), caution is still required. This is because the “social insurance” form of Canadian universal health insurance operates from very different principles than that of private health insurance which is based on the principles of actuarial fairness (Stone, 1993). The cultural, historic and legislative context of service provision may also limit applicability of research. There may be important differences in population characteristics and rights of “minority” populations in other countries. For example, while Canada has a number of immigrants from Latin America, in many of the U.S. centres where research on “Hispanic” health needs takes place, Hispanics form a significant percentage of the population, and are gaining increased legal rights as well as service access. This situation is rarely experienced by minority groups in Canada.

While it is not advised to apply evidence related to health inequities in the health system of one country to the system of another, the same limitation does not apply to examining findings on the *effects* of such inequities. For example, the effects of language barriers or low literacy on participation in preventive programs appear to be similar.

Measuring the Size of Underserved Populations

For all groups, difficulties were identified in determining the size of the populations. Difficulties in estimating the proportion of those with alternate sexual orientations are related to lack of research (particularly related to two-spirit, transgendered people, and gays and lesbians from Aboriginal and ethnic minority communities), lack of conceptual clarity, sampling limitations, “invisibility” of the population and reliance on self definition (Ryan et al., 2000).

While there are clear definitions of Registered Indians, varying estimates of Aboriginal peoples are obtained depending on definitions used, and a recent change in census questions has resulted in increased numbers of those reporting Aboriginal heritage. These figures are also affected by an individual’s willingness to be identified as Aboriginal.

Population estimates of persons with disabilities are influenced by the definition of “disability” utilized.

While precise figures of immigrants arriving in Canada are available by year, country of origin, age, gender and immigrant class, estimating populations of specific immigrant groups by province or city is not as straightforward, as total population may change due both to migration and to births/deaths within each group. In addition, available public access data (e.g. in the population health survey) often fails to differentiate between immigrants from various regions of the world in a meaningful way.

Measuring Access

Much published research that attempts to measure, rather than describe, access of underserved populations has used *utilization* as a measure of access. There are serious limitations in equating access with utilization as differences in utilization may or may not indicate problems with access. For example if a certain group (e.g. immigrants, or Aboriginal people) is found to have similar levels of utilization as the overall Canadian population, this could mean that the population:

- ◆ is of equivalent health status as the general population and uses health services similarly;
- ◆ is healthier than the general population but uses services more than are needed;
- ◆ is sicker than the population but due to access barriers uses services less ;
- ◆ has different patterns of service utilization (e.g. uses fewer preventive, but more acute, services);
- ◆ is of lower health status than the general population but relies on resources outside of the health system

Depending on the size and diversity of the population measured, reliance on measures of utilization also risk masking different patterns of use within the population. For example, some ethnic groups may utilize far more services, and some far fewer than the general population due to differences in access; with the result that the total “immigrant” or “Aboriginal” population has equivalent rates of utilization as the general population. Different types of access barriers may have differential effects on utilization.

There are a number of other limitations to using utilization data to measure access.

- ◆ Optimal utilization is unknown; we can only compare rates of utilization between groups.
- ◆ Much utilization data is based on hospital activity; it does not give insight as to use of preventive and community-based services. This is of particular concern as the literature review indicates that the greatest barriers may be experienced in accessing preventive/health promotion programs.
- ◆ Access to various services is achieved through different routes, indicating the effect of different factors. Although initial primary care contact is usually patient-initiated, much utilization is determined by physicians (e.g. return visits, prescriptions, specialist referral, hospital admission).
- ◆ Utilization is influenced by availability and accessibility of health care providers, which may differ between populations. Use of utilization data for planning purposes then risks perpetuating inequalities in existing allocation (Eyles and Birch, 1993), and may mask important problems in access.

There appear to be two reasons for the reliance on utilization data to estimate access. The Canadian literature on the utilization of health care across population groups in many ways reflects the philosophy and concerns of legislation underlying the medicare program; ensuring that Canadians of all income levels had equal access to (use of) care. The major focus of research has historically been on the relationship of income and health; access has been measured by examining the relationship between utilization and income. However, the use of utilization data to measure access can perhaps best be understood as “measuring the information we have”. Until recently, little attention has been paid to the different types of information required for decision-making (Hutchinson and Abelson, 1996). Utilization data appears to be used because it is one of the few forms of data readily available, without careful consideration of what the data represents. So while members of underserved populations use the term “access” to describe availability, ease of contact, linguistic/cultural sensitivity, and satisfaction that equivalent quality care is received, many researchers define access simply as utilization.

Defining Barriers

Issues related both to health status and access to health services for members of underserved communities are complex and overlapping. Generally the literature does not clearly differentiate between a number of characteristics which have the potential to affect access to health services; instead, groups are compared based either on “ethnicity”, or on Aboriginal or immigrant status.

Ethnicity

The concept of *ethnicity* to describe or explain barriers is problematic as the concept is rarely defined but is often based on the hypothesis that culturally based, traditional health beliefs act as a barrier to access and utilization of services. The focus on simply measuring differences between groups based on some measure of ethnicity, without adequately deconstructing the concept of ethnicity, poses a number of risks. A primary risk is the tendency to explain the “access problem” in terms of individual cultural incompetence, or even to blame minority communities for what is believed to be the impact of “traditional beliefs” or “cultural” behavioral patterns (Kaufert, 1990). As a result, researchers may conclude that minority patients are “non-compliant”, mistrustful or fearful, (Orr et al., 1990) or “reluctant”. Many stereotypes about ethnic differences fail to be confirmed by objective research.

Cultural Barriers

The concept of cultural barriers is linked to the concept of ethnicity. Discussion of access barriers experienced by or facing ethnic groups often fails to differentiate between:

- ◆ *cultural beliefs* which may result in different priorities, health practices, or confidence in prescribed treatment;
- ◆ *information gaps* as to what services are available, how they should be used, expectations of patients, or rationale for certain health practices and treatment options;
- ◆ *language / communication barriers* ;
- ◆ *racism or ethnocentrism* within the health system and their effects on utilization patterns, treatment and outcomes;
- ◆ *differences in need for, or effectiveness of, prescribed treatment* due to differing risk for

disease, prevalence of conditions, or metabolic differences within an ethnic group (Harrison, 1994; Seth et al., 1999).

Interpretation of differences between groups may be ascribed to various “causes” depending on the definition of ethnicity, or “barrier” utilized. For example, those comparing different racial groups may ascribe differences to systemic racism; those who allocate subjects based on ethnic origin may focus on the likelihood that “cultural beliefs” may create barriers. When immigration status or time since arrival in the country is considered, the focus may be “acculturation” as a concept. Traditionally, language access as the focus of comparison has been ignored (Bowen and Kaufert, 2000).

Recent research has begun to challenge the assumption that “cultural beliefs” or cultural differences are the cause of major barriers to access, pointing instead to communication barriers, systemic bias, and lack of flexibility in program delivery (Waldram, 1990; Jenkins et al., 1996; Naish et al., 1994; Perez-Stable et al., 1990). Because other populations such as gay, lesbian and bisexual people report similar difficulties in obtaining satisfactory care within the health care system, we are alerted to the limitations of explanations of barriers framed in terms of “ethnic” or “cultural” differences.

Ethnic Identifiers

In Canada, little available data is linked to ethnic origin, and the topic remains controversial. The main argument against such linking is that “ethnicity” is not well defined, it does not take potentially confounding variables into account, and so may lead to incorrect conclusions. Differences attributed to “ethnicity” may be the result of income-related factors, or inability to communicate in an official language (Robinson, 1998; Bowen and Kaufert, 2000). If correlations are found they provide little insight into underlying causal mechanisms (O’Loughlin, 1999), and may contribute to a focus on “cultural differences” instead of systemic barriers. However, not including ethnic identifiers may limit the usefulness of routinely collected data to explore differences in access or disease prevalence, important aspects of research in a culturally diverse society. Linking could also allow monitoring of care to underserved groups, to determine whether there are differences in treatment based on ethnicity — a topic that

appears not to have been researched in Canada. At present the potential risks of such linking appear to outweigh potential benefits, particularly given the lack of clear definitions. Caution must be taken in using identifiers.

Measuring Prevalence of Access Difficulties

A review of published and unpublished Canadian literature found little research that attempted to measure the prevalence of difficulties with access experienced by a population. Although census and population health surveys do collect data on language and ethnicity, with the exception of measures of “unmet need”, these data have not yet been used to develop preliminary estimates of the number of persons who face barriers to care, or what form these barriers may take.

Questions related to self-reported need for health care are often used in surveys. This method also brings a number of limitations. In addition to those inherent to the method (Eyles and Birch 1993), differences between cultural or ethnic groups in identifying and discussing health conditions; language difficulties, and distrust or fear of how results may be used, may affect the number of unmet needs identified (Anderson et al., 1993; Stevens, 1993a). Measuring differences in perceptions of unmet need relies on a shared conception of what a health need is, and expectations of what the health system should provide. It has been found that some immigrants from lower socio-economic levels learned in their country of origin to have low expectations of the health system; they were often unable to afford care, and were even subjected to abuse by the system (Bowen, 1999). These individuals are often found to be highly satisfied with Canadian services and report few unmet needs, even if faced by communication barriers, and lack of cultural competence of providers. This is the opposite pattern expected by researchers (Dunn and Dyck, 1998), in which people of lower income generally report a greater number of unmet needs.

Limitations of Available Research

Currently much of the research related to needs, utilization and effects of interventions which is used for planning purposes relies on secondary analysis of large data sets collected for other purposes, such as claims data, or population health surveys. This approach is of limited

usefulness at this time in assessing differences between underserved groups and the general population because the data necessary to undertake the analyses is not routinely collected.

In Canada, provincial claims systems record data on inpatient and outpatient service utilization patterns, diagnostic and service information, mortality and morbidity, codes and information on admission and discharge from health facilities. Some provincial health information systems record information on demographic characteristics of system users including age, gender and home address. However, (with the exception of codes that identify Aboriginal people with treaty status and designate Anglophone or Francophone patients) data on language use patterns, ethnic identity or community of origin are generally not available.

Population health surveys also face a number of limitations in assessing health status and access for underserved populations. Most surveys exclude people who cannot communicate in English or French, a group at highest risk for access difficulties (Woloshin, 1997). First Nations communities are often undersampled or unsampled. In addition to these factors, smaller surveys may be of limited validity due to sample selection, and inability to control for other confounding variables. Communication barriers, variations in cultural views of health and illness, and concerns about the purpose of the survey and meaning of specific questions, frequently affect survey responses.

Community needs assessments may provide more detailed information at a local level. Care is required in design in order to avoid the risk of undersampling due to language barriers, mobility, or small numbers of certain minority groups in some communities. Community consultations are a qualitative method often used to identify needs and perceptions of service. While useful to identify issues of concern and types of access difficulties experienced, the fact that selection of participants is often not random may preclude an estimate of the prevalence of concerns identified. However, the potential of qualitative, descriptive methods to assist in defining access, barriers, and developing strategies to measure them has not been

adequately explored, and the results have not been effectively disseminated within the health system.

Summary

In Canada, much of the research on access has focused on the variable of income. While there is general recognition that other factors such as “language/cultural barriers”, “lack of information”, or “inappropriate services” affect access, these concepts have not been critically examined in a comprehensive way.

Researchers have identified that “minorities” have generally been excluded from general health research (Frayne et al., 1996; Cotton, 1990;). Kinnon, in a 1999 review of Canadian research on immigration and health, noted the lack of research related to health service provision for immigrants; most of the identified research focused on determinants of health. Ryan et al. (2000) highlighted the gaps in research, and the negative focus on much health research related to health and sexual orientation. A number of writers have noted the absence of research related to Aboriginal people, particularly living off reserve (Wigmore and McCue 1991; Shah and Farkas; 1985; Canadian Nurses Association, 1995), and related to persons with disabilities.

Even when research is undertaken it may not focus on issues and approaches of importance to underserved communities themselves. Lack of representation of underserved communities among researchers and decision-makers appears to be contributing both to the paucity of research and the research focus itself. Clearly, more research is needed; however, research must utilize appropriate methodology. Greater attention needs to be given to clearly defining the populations and aspects of access to be measured, and to developing operational definitions and methods appropriate to the research questions and the characteristics of the communities studied. In addition, partnership with, and participation of, the populations affected are essential.

Section 4: Underserved Populations In Canada

Introduction

As indicated in the Introduction, a number of diverse populations are identified as potentially underserved by the Canadian health system. These populations include Aboriginal people, official language minorities, those of alternative sexual orientations (gay, lesbian, bisexual, two-spirited, transgendered and transsexual) immigrants, refugees, ethnically and/or racially diverse populations, persons with disabilities, the homeless, sex trade workers, and low-income segments of the population. These categories of underservice are not exclusive. Individuals may belong to more than one underserved population and face additional access difficulties related to socio-economic status, gender, or residence in an underserved region.

This section provides an overview of the evidence for underservice for a number of these populations. This initial review focuses on “separating out” complex and often overlapping issues related to access, and identifying similarities and differences in the types of underservice experienced. Discussion of underservice will be described in the following categories.

- ◆ Aboriginal peoples
- ◆ Immigrants and refugees
- ◆ Visible minorities
- ◆ Language minorities
- ◆ Persons of alternative sexual orientations
- ◆ Persons with disabilities
- ◆ Marginalized populations

In each section, key characteristics of each population, and what is known about the health status of each will be briefly summarized, utilizing previously compiled summary reports where available. Evidence for barriers to equitable care will be reviewed in the context of the framework proposed in Section Two. The focus of discussion will be the ways in which the organization and delivery of health services may contribute to inequity.

Aboriginal People

Demographic background

According to the 1996 census, approximately 3% (or 1.1 million) Canadians reported Aboriginal ancestry: two-thirds of these were North American Indian, a quarter Metis and about 5% Inuit. Over 600,000 of this number are Registered Indians (Indian and Northern Affairs, 1999). However, some provinces and territories have a higher percentage of Aboriginal people: in Manitoba and Saskatchewan they represent over 11% of the population; and approximately two-thirds of the population in the Northwest Territories, and over 20% of the population of the Yukon are Aboriginal (Statistics Canada, *The Daily*, January 13, 1998).

The Aboriginal population is diverse. There are 608 First Nations, comprising 52 Nations or cultural groups employing more than 50 languages. In terms of rights to services, Aboriginal peoples are categorized into four groups: Registered Indians, non-registered Indians, Inuit and Metis. Registered Indians also face differences in service access depending on whether they are living on or off reserve.

Most Aboriginal people (70%) live outside reserves; however, less than half of the Registered Indian population live outside reserves (Indian and Northern Affairs, 1999). The Aboriginal population is highly mobile with frequent migration between urban areas and reserve communities. Three in 10 Aboriginal people live in census metropolitan areas and a quarter in other urban areas. From 1981 to 1991, the urban Aboriginal population grew by 62%, compared to 11% for other urban Canadians. Population growth in urban areas is due both to natural increases (birth rate) as well as net migration from rural areas.

Canada’s Aboriginal population is younger than the general population, with a median age of 25.5, compared to a median of 35.4 years for all Canadians. Thirty-five percent of the population is under the age of 15, and the number of Aboriginal youth (15-24) is expected to increase by 26% from 1996-2016. The 35-54 year group is expected to increase by 41% over the same time period (Statistics Canada, *The Daily*, January 13, 1998).

Health Status

Numerous reports and statistics have consistently demonstrated a significant gap in health status between Aboriginal people and other Canadians. On almost every indicator, Aboriginal communities have lower health status (Health Canada, 1999; MacMillan et al, 1996). The Second Diagnostic on the Health of First Nations and Inuit People (Health Canada, 1999) summarizes the research in this area, recognizing that less research is available on off-reserve and non-registered Aboriginal people. A few of the issues highlighted in the report are:

- ◆ the prevalence of self-reported, major chronic diseases such as diabetes is significantly higher in Aboriginal communities than in the general population;
- ◆ there are higher levels of infectious disease;
- ◆ injuries and poisonings are the leading cause of death in First Nations populations;
- ◆ alcohol and other substance abuse is considered to be a significant problem in Aboriginal communities;
- ◆ suicide is two to seven times higher than in the general population;
- ◆ infant mortality is 3.5 times higher for First Nations
- ◆ the rate of pregnancy among young adolescent women (under age 15) are 18 times higher on reserves than for the general population;
- ◆ life expectancy for registered Aboriginal people is seven years less than that for the overall Canadian population; and
- ◆ three-quarters of Aboriginal women report experiencing family violence.

Many Aboriginal people have been exposed to additional health risks. First Nations communities face higher risk of environmental contaminants due largely to a diet of fish and marine animals together with pollution of the environment in the North.

Access to Health Services

A review of the literature indicates that Aboriginal peoples face significant difficulties in access in all four categories outlined in the conceptual framework. However, the actual issues faced vary significantly by both location of residence and by status.

Availability of services

Many First Nations people live in remote areas where there is limited access to health services funded by the provinces. In these locations the First Nations and Inuit Health Branch of Health Canada is responsible for providing primary health services. Services provided may be through physicians (often provided on a visiting or rotating basis), nurses and Community Health Representatives. These services, which include prevention and health promotion, treatment, and emergency services are delivered out of health centres, or nursing or health stations, depending on the size of the community. Community Health Representatives are local Aboriginal workers, originally intended to provide translation and liaison functions. They now also function as educators, counselors and facilitators, although their role has not yet been fully developed (Allen, 1993; Lavallee et al., 1991). Special programs related to addictions, AIDS education and prevention, and environmental health, as well as some hospitals and residential treatment centres are also provided.

Due to the isolation of many communities, provision of community health services may not be in the same form as those available to other citizens; some services may not be available at all. In some areas services delivered by the First Nations and Inuit Health Branch may be equivalent to, or better than services, in similarly remote non-Aboriginal communities. These services include emergency care/transportation, immunization programs, and prevention activities. Nevertheless, almost half of respondents in the First Nations and Inuit Regional Health Surveys believed that First Nations and Inuit people do not have the same level of services as the rest of Canada (Assembly of First Nations, 2000a).

The First Nations and Inuit Health Branch is not responsible for health care to “non-registered Indians”, or for provision of services to Indians living off reserves. Aboriginal people living off reserve (including non-registered Aboriginal people and Metis), have the same availability of insured health services as other residents.

Financial barriers

Experience with financial barriers to health services varies with status (registered or non-registered), and with third party payers for non-insured benefits, similar to other Canadians. Registered Indians and Inuit are eligible for

Non-insured Health Benefits (NIHB), a program of the First Nations and Inuit Health Branch that provides supplementary benefits to eligible First Nations and Inuit to meet medical or dental needs not covered by provincial/territorial or third party health insurance plans. These benefits include dental, vision, and pharmacy, medical supplies, equipment and transportation, crisis intervention, mental health services and health premiums in Alberta and British Columbia. In some regions they may also cover traditional healing. The provision of supplementary benefits through NIHB means that Registered Indians (whether or not they live on reserve) and Inuit have greater access to many services than non-registered Aboriginal and Metis people (or other Canadians who lack third party insurance).

Costs of NIHB have escalated over past years with the result that there is tension between the federal government and First Nations communities related to the drive to cap funds to this program. The Assembly of First Nations has claimed that per capita government spending on Aboriginals is lower than that spent on other Canadians, in spite of lower health status and higher health needs.

Another area of cost is related to lack of local services. Many Aboriginal people needing treatment may be required to travel hundreds, or even thousands, of kilometers for care. They may be required to spend weeks or months separated from their family and community, even for non-critical life events such as childbirth.

Non-financial barriers to presentation of need

Aboriginal peoples may face significant barriers in this category, although experience varies by location of residence. First Nations people on reserve may experience fewer barriers to presentation of need due to availability of community-based services, and fewer language/cultural barriers to delivery of preventive/promotion services. Understanding how the system works and how and where to access services is an important problem for Aboriginal people who migrate to urban centres. Some are monolingual and face language barriers to initial access. Inuit peoples may face an even greater challenge as many speak neither English or French, and there are fewer urban Inuit organizations to assist in providing access services. To get some health services patients must show proof of registered status; Inuit families do not always know how to get this information or

identification number (Canadian Nurses Association, 1995).

Jurisdictional confusion over responsibility for health service coverage presents difficulty for many Aboriginal people. A critical factor in initial access is the distrust and discomfort with health and social service systems experienced by many Aboriginal people, based on personal and historical experience. Lack of confidence in equitable treatment, intimidation and fear of discrimination may result in avoidance of certain types of services (Aboriginal Health and Wellness Centre of Winnipeg, 1997; Canadian Nurses Association, 1995).

Aboriginal populations have been found to have lower participation in preventive programs such as cervical screening and mammogram (Roos, 1999; Calam et al., 1992; Hislop et al., 1996; Grunfeld, 1997; Deschamps et al., 1992; Clarke et al., 1998). Low literacy and socio-economic status, as well as limited availability of linguistically and culturally appropriate health promotion and disease prevention information, likely contribute to these lower rates.

Equitable quality of care

Aboriginal peoples in Canada face significant barriers to appropriate and equitable treatment: in referring to the framework developed in Section Two, we find that difficulties are reported in all categories.

Communication with health providers remains an important barrier. With the exception of some hospitals in major centres, translation services for Aboriginal languages generally aren't available, and patients must depend on informal translation (Kaufert and O'Neil, 1998). A vast body of literature has highlighted the risks related to impaired communication. (Please see Section 4C, Language Minorities.)

Lack of respectful or compassionate treatment, as well as experience of overt racism and discrimination is commonly reported by Aboriginal people (Aboriginal Health and Wellness Centre of Winnipeg, 1997; Canadian Nurses Association, 1995). The assertion that many providers do not understand or appreciate Aboriginal culture, traditions or experience is supported by recent Canadian studies which found that many health professionals in training received limited exposure to cultural issues (Flores et al., 2000; Redwood-Campbell et al., 1999).

Many (though not all) Aboriginal people have a different concept of health and healing than other Canadians. The use of a “medical” model and its emphasis on curative services and physical health does not reflect the First Nation understanding of health as balance between mind, body, spirit and emotion, and harmony between people and the environment (Favel-King, 1993). A number of Aboriginal people base health beliefs on a traditional holistic model, and may wish to incorporate traditional healing such as the Medicine Wheel, smudging or sweat lodges into treatment. However, there is a lack of awareness and availability of traditional healing and there may be specific regulations which forbid certain practices (such as smudging ceremonies in hospital). There is a need for the option of services based on traditional practices, and for Aboriginal peoples to be in control of design and administration of health services for their communities.

However, the focus on “cultural differences” as a barrier to health access should be responded to with caution. There is clearly a great deal of concern expressed by community members about how they are treated by the health care system., but it is less clear that “cultural beliefs” are truly the key source of access barriers. A focus on “cultural differences” risks attributing difficulties to the community rather than to how health services are delivered and the biases of providers. Characteristics that result from poverty or other factors may also be attributed to “culture”.

Barriers experienced in this category vary based on location of residence, and whether and at what stage health transfer is occurring in specific First Nations communities. Some preliminary evidence suggests that communities that have transferred, or are transferring, may be more satisfied with services (Assembly of First Nations, 2000a; Shibogoma Evaluation Committee, 1999). Certainly the intent of transfer is to make health services more appropriate and accountable to the community. However, Gregory et al. (1992) in their evaluation of one First Nations Community concluded that the policy does little to address underlying socio-economic conditions. Little information relating to evaluation of the transfer process is currently in the public domain. In addition, most health services to Aboriginal people are not provided on reserve. Many registered Aboriginal people migrate to off-reserve rural or urban areas, or are forced to travel to larger centres for treatment. Many Aboriginal people are

not “registered” and less is known about the health status and needs of this group (Wigmore and McCue, 1991) due in part to the inability of current data collection systems to identify groups other than “registered Indians”.

Immigrants and Refugees/Visible Minorities/Language Minorities

A number of issues related to “ethnicity” were summarized in previous sections. Many studies on immigrant health fail to differentiate between a number of characteristics that may contribute to access difficulties. Immigrants, for example, may or may not: bring health beliefs which differ from that of general Canadian population; be fluent in English or French; be a member of a visible minority group; or, belong to a population with increased risk for certain diseases. Often immigrant and visible minority health issues are combined, although there may be very different factors affecting access. This section discusses issues related to immigrant status, visible minority status, and official language fluency separately, in an attempt to help clarify the range of factors that may have a differential impact on various immigrant and non-immigrant ethnocultural groups.

1. Immigrants and Refugees

Background

In 1996, 17% (approximately 5 million) of the Canadian population were born outside of Canada. However this figure masks a diversity which has significant implications for health needs and services. It includes all residents who are not Canadian born; newly arrived and those who have lived in Canada for decades, various classes of immigrants, (including refugees), fluent English/French speakers and those who speak neither official language, professionals and those with little formal education and from impoverished backgrounds. Immigrants come from all regions of the world and from many different ethnic or cultural groups.

In 1997, approximately 190,000 immigrants arrived in Canada. In the five year period, 1995-1999, the total was over one million (Citizenship and Immigration Canada, 2000). The majority settle in large urban centres, particularly Toronto, Vancouver and Montreal, but there are many smaller newcomer populations in most cities and larger towns in Canada.

The shift in source countries of immigration is a factor in equitable delivery of health services. The majority of immigrants used to come from Europe, the British Commonwealth, and the USA; more recently, newcomers are from Asia, Africa and Latin America. Immigrants from these areas are far more likely to face both language barriers to care and cultural differences. Immigrants today are also more likely to be visible minorities and so may face a different reception upon arrival than European immigrants.

Health Status

Immigrants recently arrived in Canada tend to be in better health than Canadian-born residents. Immigrants, particularly those from non-European countries, appear to have a longer life expectancy and more disability free years. This is attributed to the “healthy immigrant effect” (people who immigrate tend to be in better health), and to Canada’s medical screening program (Chen, Ng, and Wilkins, 1996). However, the longer they live in Canada, the closer their health status resembles that of other Canadians.

Recent immigrants are younger than the general population, better educated and less likely to suffer from chronic diseases or disabilities (Chen, Ng, and Wilkins, 1996). Many groups show lower rates of negative personal health practices such as smoking or alcohol use. However, some groups may have greater risk of infectious diseases such as hepatitis or tuberculosis due to exposure in country of origin. The average family income is higher among all immigrants than the Canadian born; however, recent immigrants are much more likely to be unemployed or have lower incomes, particularly if they are from visible minority populations. There is great diversity between immigrant groups and refugees tend to have higher health care needs than other immigrants.

Access to Health Services

Availability of services

Newcomers to Canada generally do not face barriers related to *availability* of services. Most are eligible for health coverage on arrival, and for the past several years, even refugee claimants have emergency and needed health care services provided under the Interim Federal Health Program.

Financial Barriers

Because many newcomers have lower incomes than the general population, they often face financial barriers to uninsured services; however, refugees are eligible for social assistance while they are seeking employment and so are often covered for many non-insured health benefits (such as dental, pharmacy, or vision care). Dental health is source of concern to many immigrants who report the lowest rate of utilization of dental services even though oral health status is lower than other Canadians (Locker et al., 1998). Because many newer immigrants are in lower income brackets, barriers to uninsured services may continue for a long period of time. Newcomers, being less established in the workforce and having lower levels of social support, may also face difficulties related to indirect costs of health care access, such as child care or transportation. As many are in jobs with limited job security and few benefits, time taken from work for medical appointments often results in lost pay.

Non-financial barriers to presentation of need

Immigrants are not familiar with the Canadian system of care and may experience difficulty in understanding how the system works, their rights to service, the roles of practitioners, management of appointments, or expectations of providers (Wlodarczyk, 1998; Stevens, 1993). For many, this knowledge gap is exacerbated by lack of English or French language fluency. While there have been a number of initiatives to assist newcomers become oriented to the system, these are often undertaken by settlement agencies, community organizations, or family members rather than the health system, and so the quality and accuracy of such orientation may vary.

There is evidence from Canada and other countries that immigrants under-utilize preventive programs. Studies focusing on participation in cancer screening programs (such as mammography and cervical cancer screening) indicate that recent immigrants utilize these services at lower rates than the general population (Sent et al., 1998; Grunfeld, 1997). Information, cultural and language barriers are usually proposed by researchers as causes of such barriers. There has been little research on concepts of health promotion and disease prevention as understood by immigrant groups (Vissandjee et al., 1998). Educators have faced challenges in getting accurate and appropriate

HIV/AIDS prevention information into immigrant communities (Lechky, 1997).

Barriers to Equitable Treatment

As indicated in the previous section, “cultural barriers” have been identified as a source of access barriers for immigrants and refugees; however, this concept is usually not defined, either by community members or by providers. Barriers are variously interpreted as “cultural differences” (undefined, but implying that patient beliefs and practices may prevent their understanding or acceptance of care), language or communication barriers, information barriers (e.g. knowledge of services, expectations), different life experiences (e.g. exposure to war related trauma), or ethnocentrism/racism on the part of the provider. Empirical research as to which aspect of the newcomer experience/provider-patient interaction poses the greatest barriers has not been undertaken. However, programs working with immigrants and refugees report that all of these factors play a role in impeding access. Lack of provider understanding of traditional remedies was also identified as a barrier.

Some research suggests that “cultural differences” are perceived to be a greater barrier by providers than by patients; the latter highlight communication and discrimination as larger issues. A survey of patients and providers found that while both groups identified language as a barrier, only providers focused on cultural barriers, while patients identified racism as of more concern (Chugh et al., 1993). Another study found that patients did not always understand why physicians asked questions about culture and sometimes found these questions intrusive or irrelevant (Cave et al., 1995). A study of young immigrant families found that workers identified cultural compatibility as more of a difficulty than families themselves (Gravel and Legault, 1996, abstract). A recent forum in Calgary which focused on health care barriers identified language barriers, cultural competence of providers, lack of participation or consultation with ethnocultural communities, and lack of research as important barriers (Calgary Multicultural Health Care Initiative, 2000).

Some research related to health access of immigrants has analyzed utilization of services. Generally, compared to the general population, immigrants are considered to have similar or lower rates of utilization of health services over their lifetime (Globerman, 1998; Wen et al., 1996).

According to the National Population Health Survey, hospitalization rates for non-European immigrants are lower than for European immigrants and the Canadian born (Chen, Wilkins and Ng, 1996). Emergency room visits were also reported to be lower (Wen et al., 1996). However, use of utilization data to assess access is problematic, as it is not clear whether this is a reflection of lower need, or significant barriers to access.

One of the greatest areas of need is for mental health services, particularly for refugees (Canadian Task Force on Mental Health Issues Affecting Immigrants and Refugees, 1988; Nyman, 1991). Immigrants on the whole utilize fewer mental health services than the Canadian born, although there are significant differences between various immigrant groups (Canadian Task Force on Mental Health Issues Affecting Immigrants and Refugees, 1988). Lack of awareness among health care providers of the prevalence of trauma, combined with linguistic or cultural barriers may result in providers failing to provide opportunities for disclosure. Torture, rape and war related trauma tend to be undetected by providers, who often lack the skills to identify and treat the effects (McComas, 1997).

Another factor related to impaired access is the traditional reliance on settlement or other immigrant serving agencies to provide services related to health access. One common role is the provision of language or cultural interpretation to enable access to health services. It has also been observed that immigrants presenting mental health, addictions, or health education concerns are often referred back to immigrant serving agencies for service, even though these providers do not have the specialized training needed, as the specialized services do not feel they can address the language or cultural barriers involved (Canada’s Drug Strategy, 1996; Stevens, 1993). This has the effect of creating two very different standards of service: trained professionals for English and French speaking citizens and generic settlement workers or unpaid volunteers for new arrivals.

Kinnon (1999) notes that access is an area in which the distinction between recent and more settled immigrant populations is critical, and urged further research to explore the lack of access and need for appropriate service. Access also appears to be affected by the size and “institutional completeness”^c of immigrant communities (Baker, 1993). Newcomers who

arrive in centres where there are fewer individuals from their community of origin, particularly those settling in rural areas, will face significantly higher barriers to access. There is greater likelihood of cultural and linguistic barriers and inadequate social support.

2. Visible Minorities

The literature often includes issues related to access to health services for visible minorities^d with discussions on access for immigrant communities. However, one-third of visible minority persons living in Canada were born here. (Statistics Canada, *The Daily*, February 17, 1998) It is important to separate out issues of access faced by this population, as difficulties are more likely to be due to systemic discrimination than to information or language barriers. However, visible minority status is not generally identified in utilization statistics.

In 1996, Canada was home to 3.2 million persons who identified themselves as members of a visible minority. They represented 11.2% of the total population in Canada, up from 9.4% in 1991 and 6.3% in 1986. Three-quarters of this number lived in Ontario and British Columbia, where they formed 16% and 18% of the population respectively (Statistics Canada, *The Daily*, February 17, 1998).

There has been little attention in Canadian research to access issues related to visible minority status. Community consultations often identify experiences of discrimination and racism reported by members of visible minority groups (Sharif et al., 2000); however, because participants in such activities are usually not randomly selected, their experiences may or may not be representative.

3. Language Minorities

Background

There are four populations who may face access barriers due to language: Aboriginal people, immigrants, people who use sign language and, depending on location of residence, people who speak one of Canada's official languages. Historically, research has focused on barriers by ethnicity rather than by ability to communicate in the language of service providers (Bowen and Kaufert, 2000). Language is often considered as

one aspect of culture. However, there is some evidence that language itself (rather than ethnicity, or socio-economic factors) may explain some differences in satisfaction, utilization and outcome. In this section we briefly review some of the evidence of barriers to health access which appear related to language rather than ethnicity / culture/ or socio-economic factors.

A number of immigrants do not, even after several years in Canada, speak English or French well and lack the language skills to communicate even basic health problems in English. The mother tongue for 17% of immigrants in Canada is neither English nor French; 10% speak a non-official language most often at home. Forty-two percent of immigrants speak neither English nor French on arrival in the country. There has been an increase during the last decade in the percentage of all residents who speak neither official language (approximately 2%) (Marmen and Corbell, 1999). These individuals are more likely to be women with young children, the elderly, the poorly educated, or those suffering traumatic events or psychological disorders (Stevens, 1993a). These same groups have been demonstrated to have most need of health services (Kinnon, 1999).

Many Aboriginal people, particularly the elderly or those from isolated areas, continue to face serious problems in communicating with providers. One-quarter of Aboriginal people report a mother tongue other than English or French (Statistics Canada, *The Daily*, January 13, 1998). With the exception of the Territories and Nunavut, Aboriginal languages have not been subject to the access regulations governing official languages. However, federal administrative and service delivery systems, such as the First Nations and Inuit Health Branch of Health Canada, have provided interpretation services for providers in northern communities. While 80-90% of urban Aboriginal people in Eastern Canada speak some English, in Western cities a high proportion of elders and many youth lack the functional language capability to communicate in encounters with the health care system. The needs of urban Aboriginal people were not seen to be the primary target population for interpreter services provided by First Nations and Inuit Health Branch, although hospital-based programs such as those in Winnipeg, Brandon, Thompson, and Regina serve the needs of all Aboriginal people who require language access interpretation.

^d Visible minorities are people other than Aboriginal Canadians who are members of a race other than Caucasian.

Speakers of one of Canada's two official languages may also, depending on place of residence, face similar language access needs as Aboriginal and immigrant populations.

Provision of ASL (American Sign Language) interpretation for the deaf community has followed a different path; that of advocacy for *disability rights*. These rights are more clearly specified in Canadian rights legislation, and have been the subject of a greater number of legal challenges. A recent Supreme Court decision (*Eldridge v. British Columbia*) ruled that hospitals were required to provide interpretation services for deaf patients (Stradiotto, 1998).

Access to Health Services

The literature review identified little Canadian research focusing specifically on the effects of language barriers on access, although some authors recognize language as an important barrier (O'Neil, Kaufert and Koolage, 1990).

A preliminary review of the international literature identified several studies focusing on language and immigrant communities but few on Aboriginal language access (Bowen and Kaufert, unpublished). Language barriers were found to be associated with:

- ◆ *service utilization* (preventive or primary health programs, cancer screening programs, number of tests ordered, hospital admission, use of emergency department, utilization of specialist services, staff time, referral for follow up care);
- ◆ *health outcomes* (misdiagnosis, reported problems with care, decreased care, self reported health status, poorer treatment outcomes, differences in prescribing, invasive procedures, palliative care);
- ◆ patient satisfaction;
- ◆ *patient "compliance"* (understanding of discharge instructions, diagnoses and prescribed treatment, medication errors and willingness to return);
- ◆ *health research* (exclusion of minority language speakers from health research and clinical trials);
- ◆ knowledge of conditions and diseases.

A comprehensive review of the research on language access in health care, and the implications for Canadian providers, can be found

in the report "Language Barriers in Access to Health Care". (See Section II.)

In spite of compelling research which describes the negative impact of language barriers on patient care and the recognition that such barriers may result in the violation of patient rights, few health jurisdictions or institutions have implemented policy that would require some form of language access service to be provided to all patients. Few professional interpretation programs are available; most interpretation for health needs is provided on an ad hoc basis by family members, community volunteers, or hospital/community agency staff (e.g. language banks). Use of untrained interpreters may pose more risk than no interpreter at all, as they provide a false sense of security to both provider and patient that accurate communication is actually taking place (Office of Minority Health, 1999). They also expose providers to liability as there is no guarantee that informed consent is obtained or that serious diagnostic / treatment errors are not being made (Tang, 1999, Kaufert and O'Neil, 1998; Stevens, 1993b).

Although Aboriginal, immigrant and deaf communities face similar difficulties in communicating with health providers, advocates and language service providers often work in isolation from each other. This is because responsibility for service is often not within the health system, but assumed by a variety of community groups who have a more general mandate regarding services for a specific population. This review did not identify any studies related to the applicability of research undertaken on one language group to other constituencies. The Eldridge ruling stated that:

"Interpretation services should not be conceived of as "ancillary services", which, like other non-medical services such as transportation to a doctor's office or hospital are not publicly funded. Effective communication is quite obviously an integral part of the provision of medical services" (Eldridge v. British Columbia [Attorney General], 1997).

However, the ruling was carefully stated to say it applied only to interpretation for deaf patients. Although the principles outlined in the judgement apply also to speakers of minority languages, the question is open as to whether the ruling will strengthen rights to interpreter services for other minority language populations.

The Importance of Literacy

Recent research has highlighted the correlation of literacy with health status and health outcomes (Perrin, 1998; Sarginson, 1997). Low literacy rates have been linked to lower health status, increased rates of hospitalization, poor understanding of health conditions and any instructions related to discharge from hospital or medications (Baker, 1999). Literacy is also a factor in being able to benefit from the opportunity from health promotion or disease prevention information (Sarginson, 1997).

Literacy is correlated with low socio-economic status as many individuals with low literacy are poorly educated, and therefore have lower incomes. However, individuals who are not fluent in English or French experience low levels of literacy in Canada's official languages, no matter what their level of education, or literacy in other languages.

Alternate Sexual Orientation

The term "alternate sexual orientation" is used to describe gay, lesbian, bisexual, two-spirit^e, transgendered and transsexual individuals. While it is not possible to validate estimates of the percentage of gay men and lesbians in the population (and estimates continue to be contested), the commonly used figures are 10% of males, and anywhere from less than 1% to 8% of females, respectively (Ryan et al., 2000).

Health Status

Because individuals of alternate sexual orientation come from every sector of society, they are at no greater risk of impaired health status related to socio-economic factors than other Canadians. Nor is there evidence of any diseases specific to sexual orientation, although certain personal practices may put specific individuals at greater risk. A social climate of intolerance and discrimination increases the probability that individuals may experience social isolation, 'hate crimes', or violence. This appears to place them at higher risk for depression and suicide. For example, a Calgary study concluded that men with a "homosexual orientation" were 13 times more at risk for serious suicide attempts (Badgley and Tremblay, 1997, abstract). Mental health problems, substance abuse and engaging in high

risk sexual behaviours also appear related to the homophobia and heterosexism experienced in the wider community (Ryan et al., 2000).

A recent literature review (Ryan et al., 2000) concluded that gay and lesbian persons do not necessarily have different physical health needs. However, health needs and concerns may differ from that of the heterosexual population (Moran, 1996). The "coming out" process is identified as a crucial component of health for which support is rarely available. The heterosexism and homophobia experienced in the larger society and within the health and social services systems also results in specific mental health needs. The review by Ryan et al. (2000) also identified that little research or other information in the literature was available related to health status and access issues of transgendered and transsexual people.

Access to Health Services

In reference to the framework outlined in Section 2, persons of alternate sexual orientation do not face barriers related to availability or financial barriers to non-insured services at a greater rate than the general population (although persons with HIV/AIDS have been refused service in some situations). Barriers to access identified in the literature fall almost entirely in the categories of barriers to equitable quality of care although barriers to presentation of need also exist. These barriers include:

- ◆ overt prejudice and discrimination, leading to a feeling of being unsafe within the health care system;
- ◆ an atmosphere which creates distrust and fear of "coming out", impairing communication with health providers, and resulting in avoidance of care;
- ◆ lack of research on health issues of gay and lesbian persons, their exclusion from general research, and reluctant participation in research;
- ◆ and, ignorance among providers on issues of sexual orientation, and health needs of gay, lesbian and bisexual people.

There is no doubt that discrimination and homophobia confront those of alternative sexual orientation, or that the health system itself has played a key role in this discrimination. This is because historically those of alternate sexual

^e Two-spirit persons are Aboriginal people who are attracted to persons of their own sex, or who are transgendered.

orientations were defined by the medical community as 'sick' or mentally ill. Until 1973, the Diagnostic and Statistical Manual of the American Psychiatric Association listed homosexuality as a psychiatric disorder. Certain health care providers are reported to continue to have a heterosexist and anti-gay and anti-lesbian bias (Ryan et al., 2000).

Attitudes of physicians, ignorance of issues, and scarcity of supportive providers have been the source of complaints about physician services. Disclosure of sexual orientation was identified as being the greatest problem in consulting a health care professional or gaining access to treatment.

In addition to heterosexist or homophobic reactions, patients also find that providers are ignorant of issues of sexual orientation, and may tend to see health issues specifically related to sexual health. Health needs of gay men may be defined in relation to HIV. Underscreening may occur for certain conditions, such as screening for cervical cancer or vaginal infections of lesbian women (Moran, 1996). Most often providers assume that clients are heterosexual (Mathieson, 1998). Policies may also be discriminatory; for example, hospital policy may limit visits to intensive care, or release of patient information, to "immediate family" which discriminates against same sex partners.

Some groups feel the impact of these barriers more than others. Two-spirit persons, rural residents and ethnic minority communities face even more significant barriers to access. Particular problems were reported by gay men and lesbians with disabilities (Ryan et al., 2000).

Persons With Disabilities

Health Status

In 1991, 4.2 million citizens, or 15.5% of the Canadian population reported some level of functional disability (*The Daily*, 1992; Oct. 13 1-4). The Canadian Mental Health Association estimates that one person in three will have a mental illness in his or her lifetime. Given the aging of the Canadian population, and the continuing advances in medical science, it is expected that the percentage of Canadians with disabilities will rise and that most individuals will have some sort of disability at some point in their lives. The category of persons with disabilities is diverse, and includes individuals of all ethnic and cultural backgrounds, and of all sexual

orientations. In addition, individuals may be living with one or more different types of disability (mobility problems, sensory impairments, lack of strength, coordination or comprehension) which present different problems with health care access.

Persons with disabilities have a high level of unemployment, and are among the poorest in the society (Human Resources and Development Canada, 1999). In addition, they have less formal education than the general population. Forty-five percent of the respondents to the Health and Activity Limitation Survey with severe disabilities had eight or fewer years of education (Statistics Canada, 1992). Both physical barriers and attitudes of the non-disabled population contribute to social isolation and low status. Some people with disabilities are at higher risk of violence and abuse. Persons with mental illness appear to be at greater risk for injection drug use and HIV infection (Davis, 1998). Some underserved groups have higher rates of disability than the general population; for example, over 30% of Aboriginal adults report a disability (Ng, 1996; Human Resources Development Canada, 1998).

Persons with disabilities have been excluded from full participation in most areas of life. Over the past two decades, there has been increasing advocacy for self determination and equal access to services, and a shift from a support and dependence orientation, to one which emphasizes promoting empowerment, consumer control, providing options and choice and encouraging inclusion and participation (P. Hutchinson et al., 2000).

Access to Health Services

Barriers to health care are both physical and attitudinal, and vary based on the form of disability experienced by the individual.

Many people with disabilities, particularly those in rural areas, may lack availability to specialized medical care or the support services needed to maintain independence in their communities, forcing them to move away from family and community (Peat, 1997; Wilson et al., 1995). Aboriginal people in particular are at risk (Fricke, 1998). Choices of providers may also be limited by physical location, training of providers or willingness to provide services to those with disabilities (Milne et al., 1995). Because of low income, and additional costs associated with the

disability (e.g. transportation, or communication aids), financial barriers to non-insured services are also an important concern.

Barriers to presentation of need are often experienced, many of which are physical barriers. While Canadian human rights legislation makes a general commitment to accessibility for persons with disabilities, there is no enforcement structure (such as provided by the *Americans with Disabilities Act* in the U.S.). Transportation to health services is often a major problem, and facilities themselves are often not barrier-free.

Social isolation, low literacy, or learning or intellectual disabilities may contribute to low awareness of services, and how to access them. Attitudes to those with disabilities may also prevent access to certain kinds of information, such as sexuality education (Stevens et al., 1996). Those with sensory or intellectual/learning disabilities are particularly at risk for barriers to preventive and health promotion information and programs. Specialized programs often do not tailor services to meet the needs of people with disabilities.

Persons with disabilities may also face a range of barriers to equitable care. Once inside a facility, there may be other physical barriers. These may include such varied factors as inaccessible washroom facilities, lack of accommodation in waiting areas for special seating, inaccessible examining tables, failure to provide patient information in a variety of formats (e.g. Braille or audiotape), lack of interpreters or telecommunications devices (e.g. TTY/TDD) for deaf patients, and the constraints of special transportation systems which can make scheduling difficult (Jones and Tamari, 1997).

The most important barriers are attitudinal, however (Peat, 1997; Moore, 1997). Traditionally, the health system has focused on disability as an individual physical impairment and ignored the social dimensions of disability. The definition of disability as a deficit and the focus on rehabilitation as a cure may create a number of problems. The disabled consumer movement has rejected the definition of persons with disabilities as “sick” or “impaired”, and encourages people with disabilities to take control of their own lives and their own health care.

Persons with mental illness face unique problems in availability of mental health services. Patients and their families often express greater needs for service than case managers (Calsaferrri and Jongblood, 1999). Many individuals with a

psychiatric diagnosis do not report using mental health services (Parikh et al., 1997).

Characteristics of the illness may contribute to lack of recognition of need for care or avoidance of care, and those who present with the most disruptive behaviour may be assessed as having behavioural or justice related problems.

Mental health services have been the focus of particular concern regarding equitable access of disadvantaged groups. Aboriginal people, immigrants and refugees, or persons with other forms of disability, face particular challenges to getting the mental health care they need. Assessment and treatment of mental health conditions are heavily impacted by the cultural assumptions of both provider and patient; and many services are “verbally based”, leading to potential discrimination against less well educated segments of society, or those facing language or cultural barriers.

Marginalized Groups

In this paper, groups that are marginalized due to characteristics or behaviours, or who are considered particularly vulnerable, are defined to include individuals who are homeless, mentally ill, street youth, injection drug users, and sex trade workers.

While this category includes diverse groups with different needs, there are also a number of similarities in the types of access issues faced and potential responses to health service needs. There is an overlap between marginalized groups; many marginalized people face multiple risk factors. In addition to poverty, many in these populations are socially isolated and lack family support; few are employed.

Access to Health Care for the Homeless

Persons who are homeless are perhaps the most marginalized of the poor, and their numbers have been increasing. Characteristics of the homeless population have altered dramatically over the past decade. There are more women, youth, able-bodied young people lacking marketable skills, runaways, discharged psychiatric patients, women and youth fleeing domestic violence, families and single mothers on social assistance, and working poor. While the numbers of homeless have grown generally in recent years, large urban centres where there is a shortage of affordable housing are experiencing the greatest increase.

This population has a very low health status. The homeless are also at greater risk for accidents and violence.

Persons with mental illness are over-represented in the homeless population; this is linked to deinstitutionalization of the mentally ill. Estimates of prevalence of mental illness among the homeless range from 30-50%. Mental illness is often coupled with substance abuse.

Aboriginal people are at greater risk for homelessness, due not only to factors related to poverty, but also a pattern of migration between the reserve and city, and discrimination in housing. Shelters and other agencies which serve the homeless report a high proportion of Aboriginal clients, averaging 50% but rising to as high as 90% in some areas (Beavis et al., 1997).

The homeless face a number of barriers to health care access. They often confront problems of *availability* of service. A significant problem is that many do not have a provincial health card, and so may be unable to access services to which they are entitled; it is also difficult to apply for a card without identification or an address. Many individuals also report being denied service because they were not clean and presentable (*Ontario Medical Review*, 1996). Low income and few social resources also present problems in accessing non-insured services.

Homeless people also experience barriers to presentation of need. They lack transportation, find primary services unfriendly and intimidating, and often delay seeking care. Many do not know

where to seek care, many of those requiring mental health services did not know where to go (Stuart and Arboleda, 2000). They are reported to under-use preventive services, instead relying on emergency services. This is due in part to the way services are organized and the requirement that emergency departments must provide care to those who present to them. Homelessness also creates practical problems related to follow-up or communication of test results, safe storage of medications, or a place to be sent home to recuperate. And, in spite of the prevalence of serious mental illness, few mental health services are available to the homeless.

Summary

This section summarized the information related to access to health services identified by researchers and reported by various underserved populations. These populations vary significantly in health status and the types of barriers experienced. However, in spite of this diversity, there is a remarkable similarity in many of the concerns expressed and barriers identified. This suggests that there may also be similarities in the types of responses needed to address these barriers. The literature review also highlights the additional difficulties to access experienced by those who belong to more than one "underserved population", and the need for responses to address the needs of those who experience more than one form of underservice.

Section 5: Responses/Solutions

This section outlines a number of potential responses to the problems of ensuring equitable access for underserved populations. These responses are described under three headings: Recruitment and Training, Program Design and Delivery, and Policy and Structure. In each section the potential benefits and limitations of each response are briefly discussed and examples of existing programs highlighted.

Recruitment and Training

Recruitment of Health Providers for/from Underserved Communities

Recruitment of providers, particularly physicians, has been a common response to problems of medical workforce supply in rural and remote communities. There are two strategies in this category which can be applied to service provision to underserved *populations*: pre-service recruitment policies, and post training initiatives.

It is proposed that increasing the number of health professionals from underserved populations will help to address problems of both service availability and cultural/linguistic barriers to access (Royal Commission on Aboriginal Peoples, 1996; Blair, 1994). Evidence from other countries suggests that physicians from underserved populations provide service to a disproportionate number of underserved patients (Moy and Bartman, 1995). Research also suggests that many clients from “minority” populations would prefer a level of “matching” between them and their health care provider, and it is argued that this matching results in a greater level of trust and comfort (Ryan et al., 2000; Saha et al, 1999). Increasing the number of health professionals who speak non-official languages may also reduce the need for language interpretation services.

Other benefits may be less direct but are as important. Combined with initiatives in provider education (discussed later in this section), facilitating access to practice by members of underserved populations has the potential to assist in increasing cultural competence and social responsiveness within the health professions (Cappon and Watson, 1999).

Pre-service Initiatives

Approaches within this category include affirmative action policies for admission to training for health professions, and development of special programs to facilitate access to medical training for members of underserved populations. Feasibility of this approach differs depending on the population.

Creating strategies for increasing the number of Aboriginal health professionals has been identified as a priority; there are few Aboriginal health professionals, researchers or administrators. The National Forum on Health (1997) observed that for Aboriginal peoples to take control of their health and health services, they must become involved in the design, development, delivery and evaluation of services in their community, and that increasing the number of Aboriginal health professionals is necessary to accomplish this.

While there is a clear need to make training of Aboriginal health professionals through special initiatives a priority, the importance of facilitated access to professional training programs for other underserved groups is not as clear. For example, there is no Canadian evidence that a health professional from one immigrant group would address access needs of another ethnic community better than a Canadian born professional. Many argue instead for increasing the cultural competency of all providers. In a culturally diverse society it is also essential to ensure that intake policies of educational institutions are unbiased and that any barriers to representation of disenfranchised groups within the health professions are removed (Cappon and Watson, 1999).

In general, special access programs which prepare candidates from varying backgrounds to compete for available training spaces (with additional financial support if required), are more likely to be accepted than “affirmative action” initiatives, which may raise a number of legal and ethical concerns. Many second-generation immigrants to Canada are enrolling in health training programs, and the health professions increasingly reflect the diversity of the population.

Post-Training Initiatives

Post training initiatives for underserved populations focus on the recruitment and licensing of professionals trained in other countries. One example of this is the licensing of foreign medical graduates (FMGs) or international medical graduates (IMGs). Data from 1997 indicate that 25.5% of active physicians in Canada were IMGs; 46% of which were family physicians. One third of these were trained in Great Britain or South Africa (Buske, 1997).

The benefits of “selected” IMGs^f to service provision in remote rural areas has been clearly demonstrated; although their recruitment has been criticized for being a short term solution to a long term problem, and even exacerbating a problem of oversupply (Barer and Stoddart, 1999). Licensing of immigrant/refugee IMGs may also assist in addressing issues of regional supply. Concerns have been expressed that the “cultural differences” between these IMGs and the rural populations they serve may lead to dissatisfaction; however no research has been identified in this area.

The greater benefit appears to be the potential of non-selected IMGs (immigrants, refugees) to increase access for newly arrived Canadians. Many immigrants in urban areas have significant difficulty in obtaining primary care that is culturally and linguistically accessible. Many IMGs are themselves members of these recently arrived immigrant or refugee groups, and share the same language and cultural background.

Licensing of these immigrant or refugee physicians has been a controversial topic in Canada for many years. Entry into practice for immigrant or refugee physicians is extremely difficult, usually requiring post graduate training; most immigrant or refugee IMGs do not meet the requirements (Barer and Stoddart, 1999).

Many IMGs view the barriers to practice as discrimination based on country of origin (Mata, 1999; Goodley, 1992; Bowen and Simbandumwe, 1998). Most selected physicians come from Commonwealth or European countries, whereas many immigrant or refugee IMGs are visible minorities. When large numbers of individuals from particular ethnic backgrounds are blocked in their entry into professions there are often

generalized perceptions of “institutional” discrimination, whether or not that is the intent of licensing regulations (Mata, 1999). In two provinces, provincial human rights commissions have ruled in favour of IMGs who claimed that the restrictions on their entry to practice were discriminatory.

Orientation of immigrant or refugee IMGs to cultural and organizational expectations, current issues in health care reform, the importance of fluency in English and French and licensing requirements also appear inadequate (Bowen and Simbandumwe, 1998).

Finding a solution requires collaboration among all stakeholders, including provincial health departments, provincial licensing authorities, accrediting bodies and training institutions. This requires development of appropriate and unbiased screening and evaluation methods, review of licensing requirements, and funding for the evaluation and training and support components necessary for IMGs to learn about the system and update their skills (Andrew and Bates, 2000). There has also been a call for national standards and a coordinated national approach (Barer and Stoddart, 1992; Nasmith, 2000).

In 1997, in response to human rights concerns, the Royal College of Physicians and Surgeons of Canada (RCPSC) changed its policy with respect to certifying foreign-trained specialists, and in July 2000 implemented a pilot process for approval of IMG specialists.

In July 2000, the Manitoba government announced a new plan for facilitating licensing of IMGs. This initiative includes a preparatory course for those wishing to write licensing exams, a skill enhancement program, access to a conditional medical license and income and expense support (Lett, July 18, 2000). These two initiatives are recent and it is unclear what impact they will have on immigrant or refugee IMGs wishing to practice in Canada.

Although there are many reasons to address barriers to licensing of IMGs, by itself, this response is not anticipated to have a significant impact on barriers to access for newcomers. It is important to guard against the assumption that providing a physician from a particular ethno-cultural community will address all access

^f IMGs are comprised of many different groups but for the purposes of discussion they may be described generally as “selected physicians” who may be recruited to address problems in physician supply/distribution, and immigrants or refugees who apply to get into practice once they have arrived in Canada.

needs. For example, many Canadian cities have small numbers of many different ethnic groups. It is not feasible to provide primary care to all communities through a provider of the same ethnic or language background.

There is diversity within groups: placing patients with providers of the same “ethnic” or language background may actually contribute to distrust if the patient and provider are of different political, socio-economic, religious or regional backgrounds. This form of matching may also provide only partial language access where there are differing dialects or forms; significant differences in health care beliefs and practices related to socio-economic status or region may be ignored.

Physician access is only one component of health care. Comprehensive health system access necessitates dealings with many different health providers (nurses, health educators, imaging technicians, dentists, physiotherapists, psychologists, etc.). However, to date, recruitment of health care professionals has focused on issues of workforce supply rather than facilitating access for underserved populations.

Preservice and Continuing Diversity Education for Providers

One disturbing finding emerging from the literature review was the perception among all underserved groups that providers were often insensitive to their needs, or even racist, heterosexist or homophobic. Recent Canadian studies confirm that diversity training is not well-developed in Canada and that there are serious deficiencies in training for a culturally diverse society.

Exposure to cultural competency training also appears inadequate. Two recent studies focused on the teaching of cultural issues in Canadian medical schools. A study by Flores et al. (2000) found that only 27% of Canadian schools address Aboriginal issues and none had separate courses addressing cultural issues. Most offered one to three lectures. Another study focusing on exposure to Aboriginal health issues found that only one program among the 16 Canadian medical schools had formal written objectives, and most programs offered cultural curricula as an elective (often a day or a weekend), not as core curriculum. The authors concluded that while most programs provided some exposure, most needed more expertise and direction. Concern

was expressed regarding the ad hoc character of much of the training (Redwood-Campbell et al., 1999). Robb (1998) reported that only 9% of Canadian medical schools included cultural diversity in the program. Shah et al. (1996) identified three major deficiencies in Canadian educational institutions specifically related to teaching on Aboriginal issues: lack of Aboriginal content in the curricula; lack of faculty role models; and, low enrollment of Aboriginal students. They outlined the role of the visiting internship in Aboriginal Health at the University of Toronto to assist in addressing these barriers.

Canada appears to lag behind some other countries in the teaching of cultural issues (Flores et al., 2000) Topics of cultural competence must be considered “core content”, not an elective in a diverse society. It must also be recognized that there are very different approaches to teaching cultural competence. Some approaches may risk reinforcing stereotypes and contributing to less sensitive care (Carillo et al., 1999; Stevens, 1993a). The lack of expertise within training institutions poses challenges for development and implementation of effective education strategies. Teaching of issues related to sexual orientation (Robb, 1996) and disability are also necessary aspects of diversity training.

A commitment to both teaching of cultural competence and addressing prejudice and discrimination within the training environment are required if meaningful access is to be ensured for all patients. Addressing issues related to provider training appears to offer better potential for addressing access issues of immigrants, visible minority, gay or lesbian communities and persons with disabilities than attempting to “match” patients with providers of their own “background”. The emphasis must be on preparing *all* providers to deliver quality, appropriate care to the diversity of Canada’s population. Benefits of increased “cultural competence” extend beyond expected improvements in direct client service. Greater awareness and skill among health professionals will facilitate implementation of other service initiatives.

Providing cultural competence training to physicians and other health professionals already in practice presents even greater challenges. The lack of published research on issues related to diversity and access difficulties of patients contributes to low awareness of the need for on-going education in this area.

There is also a need to review and monitor selection and evaluation criteria for professionals coming into training. Currently, none of the medical school examinations evaluate candidates' commitment to social accountability (Cappon and Watson, 1999). In a culturally diverse society, openness and aptitude for working with patients from diverse backgrounds is a necessary to provide effective care.

Development and Expansion of Alternate Health Roles

Development of expanded and alternate health care roles in order to increase efficiency of health care services has been proposed consistently through a number of commissions. Barer, Wood and Schnieder (1999) highlight the potential of 'physician extenders' (e.g. nurse practitioners, and physician assistants) to address workforce supply needs in remote and rural areas. There is also the potential for such roles to improve care to underserved populations. Not all needed health services must be delivered by physicians, and some services can best be delivered by other providers, or outside of the formal health system. Alternate health roles (substituting or extending the role of physicians) can be described in two categories:

1. Roles which entail the provision of "medical service" and are covered by legislation (e.g. nurse practitioners, midwives, physician assistants)
2. Unregulated roles which do not provide direct "health care" services (e.g. health educators, outreach workers)

Provision of competent alternate providers can enhance the capability of the health system to meet a variety of needs, and in many cases provide higher quality services. Although development and implementation of such roles has the potential to increase both appropriateness and quality of care, it is important their introduction be considered for all patients (not only underserved populations), in order to avoid the perception of a "two-tier" system of care.

The Role of Academic Health Centres

Academic health centres have been established throughout Canada and are financially supported by provincial governments. In addition to their crucial role in educating health professionals (discussed earlier in this section), academic

institutions have played a direct role in provision of service to the underserved, particularly to those in remote locations.

All 18 family medicine training programs in Canada offer experiences in rural medicine. A number have instituted a range of activities to support service delivery in rural areas. Development of strategies to further engage medical schools with underserved populations has been more variable. Many schools have clinical outreach programs. A few, such as the University of Western Ontario, Dalhousie University, The University of British Columbia, and McMaster University have developed other community based initiatives ranging from working with community development projects, to telemedicine linkages, to establishing an environmental health clinic. Collaborative research with underserved communities remains generally less developed (Cappon and Watson, 1999).

Academic medical centres have the potential for a greater role in contributing to improved access for underserved groups than has been undertaken to date. They are responsible for training of future health professionals and have the potential to develop additional programs for training non-physician personnel to provide primary care access (Barer, Wood and Schneider, 1999). It has also been suggested that increased responsibility for service provision to rural and remote areas could be assigned to academic medical centres (Barer and Stoddart, 1999). This option has not been explored for underserved populations. Academic medical centres also have a potential to play a greater role in facilitating collaborative research with underserved communities.

There is increasing awareness of the need for continuing social accountability (or social responsiveness) in health professional training programs. Social accountability can be defined as the "obligation to direct...education, research and service activities toward addressing the priority health concerns of the community, region and/or nation" (Boelen and Heck, 1995). A recent survey identified the awareness of Canadian medical schools of the need to enhance social responsiveness and a willingness to explore ways of doing so. A number have initiated innovative programs in response to identified needs. Key challenges are the need for overall policy direction, systems for sharing best practices, support from federal and provincial ministries of health, and alliances with other health professionals to facilitate progress in this area

(Cappon and Watson, 1999). Another challenge is the lack of cultural diversity within the health teaching professions (Shah, 2000).

Program Design and Delivery

The complaint that services are not “accessible”, “culturally sensitive” or “appropriate” suggests a need to increase flexibility and creativity in program design and delivery. This category includes a number of different responses, only a sample of which is discussed here. It should be noted that many of these approaches also rely on alternate funding and physician payment systems, or include the participation of health related organizations outside of the insured physician/hospital care system.

Development of “Linking” Programs

This strategy focuses on creating links between providers and underserved communities. Responses can be described in two broad categories: interpreter/cultural mediator programs and community outreach initiatives.

Health Interpreter Programs

Interpretation programs are essential to equitable health care access in any situation where there are communication barriers between provider and patient. Provision of interpreters emerges as a priority response throughout the research literature and community consultations (Stephenson, 1995; Stevens, 1993; Bowen and Kaufert, 2000; Calgary Multicultural Health Care Initiative, 2000). However, in the absence of policy that requires providers to use professional interpreters, availability of these programs in Canada is uneven, as is the quality of service provided. Most interpretation is provided by family members and untrained volunteers. Traditionally, provision of language access services has not been assumed as a responsibility of the health care system itself, and there are few protections for patients related to either availability or quality of service.

There are many models for provision of health interpreter services. The feasibility of each model of interpretation varies, based not only on the number of people in a community who lack official language fluency, but a range of other factors which affect both need and availability of alternative or supplementary resources. It must also be noted that the greatest access barriers are often experienced in smaller communities; relying

on numbers alone to determine need is inadequate (Bowen and Kaufert, 2000). More research is needed to assist in determining the best model for a specific location. However, whatever model is chosen, the experience of language access programs demonstrates that several components are necessary for provision of effective interpreting programs:

- ◆ Policy requiring use of trained interpreters, combined with an enforcement provision;
- ◆ Adequate and stable funding;
- ◆ Investment in training and evaluation of interpreters;
- ◆ A professional education component; and
- ◆ Evaluation/research components.

Language access may also be addressed by provision of print or audiovisual resources in other languages. These resources have an important role in providing orientation to newcomers on the health service system, preventive information, and information on various health conditions, treatment and care. There are two general approaches to provision of resources in other languages: translation from the original English or French, and development of resources based on community needs and interests. Both require special expertise to be accurate and effective. Challenges to use of materials in other languages relate to funding, quality control, and coordination or duplication.

Community Outreach and Education Initiatives

Recognition of barriers to health promotion and disease prevention services often results in special community outreach and education initiatives. These programs, which are often provided in conjunction with interpreter services, usually provide information on service availability while addressing cultural and language barriers to initial access. Programs usually focus on disadvantaged or marginalized groups and on health concerns that emerge as priorities (e.g., HIV prevention, cancer screening). Examples of these initiatives include:

- ◆ print and audiovisual resources to provide orientation
- ◆ community-based education programs
- ◆ community-based initiatives for program development or education

- ◆ outreach workers, outreach clinics or special awareness days.

Outreach initiatives can often provide a rapid, local response to identified needs, and facilitate utilization of existing services. They can often be linked to other health, education, or social service initiatives, and are particularly effective in addressing informational barriers.

Linking programs can focus on addressing barriers to *presentation of need*, but they also play an important role in ensuring equitable quality of care by facilitating communication, and provision of services which are culturally appropriate. They may also facilitate greater participation and direction of programming by community members themselves. A limitation of such approaches if used alone is that they are often focused on “cultural differences” of clients, rather than systemic barriers to care. They are often used as an add-on, by organizations that leave their existing structures intact (James, 1998). However, they do have the potential to facilitate improvements in organizational access. Another limitation is that programs may have time limits, or be focused on a single issue. They depend on awareness and commitment of providers to identify and respond to gaps in service. Outreach programs are often developed as supplements to core programs and may rely on members of the target communities who are often hired in junior or contract positions. This leaves them vulnerable to changes in key personnel and to funding shortfall (Stevens, 1993a, b).

Population-Specific Health Services

One approach to addressing barriers is to develop services focused on specific populations. These services may be operated by hospitals, community health centres, public health departments, or community based not-for-profit organizations.

There are a number of potential advantages to population-specific initiatives in addressing access needs. These include:

- ◆ centralization of resources
- ◆ development of a “Centre of Expertise”
- ◆ an environment which facilitates confidence and participation of clients
- ◆ clear accountability for provision of access services

- ◆ greater potential for community direction and control, responsiveness to needs, and flexibility
- ◆ potential to build in bridging/advocacy functions to other parts of the health system.

However, they also have a number of potential disadvantages, which suggest that they should not be the only response to access needs. In addition to requiring a “critical mass” of clients (which means that they will not meet the needs of smaller populations or those in smaller centres), such responses risk “ghettoizing” clients. Provision of a population specific service may result in restricted choice for clients if other alternatives are not provided.

Most innovative programs combine several initiatives into their response. What these programs seem to have in common is that they are developed in response to health needs and access barriers as experienced by users. They also focus on organizational change and community partnerships.

Communication Technologies (Telehealth/ Telemedicine)

Telehealth describes the use of information and communication technology to deliver health care, health education and health information over distance. *Telemedicine* describes the delivery of medical services at a distance (Advisory Council on Health Infostructure, 1999). It has particular utility in addressing care and education to remote locations, an important issue for Canadian health care (Picot, 1998). Applications include videoconferencing, assessment, monitoring and follow up, mental health counselling, remote monitoring of blood glucose, tele-electrocardiogram, tele-monitoring of vital signs, ultrasound, tele-visitation of hospitalized family members, and patient and health worker education.

Some evaluations of telehealth applications in Canada are available. Results of these studies indicate good results both on the measure of diagnostic accuracy and patient satisfaction (Dick et al., 1999; A. Stevens et al. 1999, Elford et al., 2000; Cheung et al., 1998, abstracts), for health services ranging from psychiatric assessment to cardiac care, to ultrasound evaluation. In some studies patients record higher satisfaction than providers; avoiding travel time and costs are

highlighted as a key benefit from the patient's perspective.

Telemedicine has been identified as of greatest benefit for improving access to health services for those in remote areas (e.g. First Nations communities). Benefits are anticipated to be to the patient, to the provider and to the general community. It has been used to reduce the need to transport patients from their communities to medical facilities, increase access to specialist care, decrease the time needed to make a diagnosis, and improve monitoring of patients following discharge. It also allows greater support and education to health personnel working in isolation. The National First Nations Telehealth Project, begun in 1998, is evaluating the implementation of telehealth projects in five First Nations communities. Initial results identify a number of challenges to implementation as well as potential benefits to access. Cost effectiveness is as yet unclear (Health Canada, 2000).

The literature review did not identify use of telemedicine for the specific purpose of addressing needs of underserved populations, other than those in underserved areas. For example, many studies have identified the benefit of telepsychiatry in addressing needs related to geographic distances; however, the potential of using existing technology to link immigrant patients and providers of the same language and cultural background does not appear to have been explored. Nor did the review identify Canadian research related to remote telephone translation services, although this alternative has been investigated in the U.S. where indications were that patients were satisfied and costs were competitive (Hornberger, 1998). Telephone translation services provide access to interpreters, often on a 24-hour basis, on a fee per minute basis, and brings the potential advantages of cost efficiency and increased access for smaller language groups who can not support other forms of interpretation services. However there remain several questions related to cost, interpreter training, accountability, and quality control (Bowen and Kaufert, 2000).

Telemedicine also suggests a number of options for persons with disabilities in monitoring care, with particular potential for supporting persons with disabilities to live in their own community. It has been proposed that telecommunication technology could be used to provide rehabilitation and long-term support to people with disabilities (Burns et al., 1998, abstract). In Canada, the

initiatives in telehomecare (the use of information and communication technology to deliver and manage health services at a patient's residence) may be of particular benefit to persons with disabilities. (Office of the Health and Information Highway, 1998). It appears that the potential of telehealth applications to address non-geographic barriers to access should be further explored.

While the potential for such technology to provide increased quality of access particularly in remote and rural areas appears clear, it is beyond the scope of this report to analyze the cost and feasibility of implementation of various technologies. It is proposed that the technology can reduce costs to both the patient and health system. However, evaluation of effectiveness of the technology is still in its infancy, and there is to date little evidence related to cost-effectiveness.

There are also a number of practice issues that relate to telehealth service delivery. Fee schedules must be revised to accommodate this form of service. (Four provinces had completed this process as of July 2000.) Generally telehealth is not considered an insured service, so without formal schedule revisions, services cannot be reimbursed under provincial health insurance plans. Professionals need thorough orientation to the technology. There are still questions related to liability and insurance coverage for practice, and of licenses needed to deliver telehealth between provinces. There also remain a number of issues related to selection and compatibility of equipment.

Structure and Policy

This section outlines three areas of response which are essential to addressing barriers to access; funding models, policy development, and partnerships/participation with underserved groups.

Funding and Provider Payment

One major barrier to equitable and appropriate care is the traditional emphasis on physician and hospital services, which consume most of the health budget. A population health approach suggests that investment in health promotion and disease prevention, and community development approaches (areas which are not traditionally those of physician expertise) should be prioritized. The clearest evidence to date of access barriers for underserved populations is in the area of access to preventive and early detection

programs. The finding that current preventive services are utilized less by high risk, or underserved populations indicates that alternate models of service delivery should be considered. (Roos, et al., 1999). However, funding has not been redirected to these approaches, or to organizations with expertise in community based programming.

Hutchinson and Abelson (1996) propose that there are three models of physician primary care delivery: fee for service (the most common model in Canada at present), capitation, and community health centres. Fee for service is often considered to be the least effective payment method for ensuring population coverage of preventive programs. Physician advocates have also identified the limitations of the current fee schedule in providing reimbursement that recognizes the complexity of care for the marginalized (Pottie et al., 2000). The same fee is paid no matter how long the physician spends with a patient, which may function as a disincentive to working with patients with complex needs, or utilizing solutions such as working with a professional interpreter.

Both community health centres and capitation models have been proposed to improve participation in preventive programs. This section provides a brief overview of key characteristics of these two models, specifically as they relate to underserved populations. (It should be noted that provision of care by community health centres is an issue of funding, whereas capitation is a physician payment alternative).

Community Health Centres

Community health centres (CHCs) provide a specific response to the primary health care needs of a community. CHCs are non-profit organizations, governed by a board of directors drawn largely from the community they serve. Service is delivered through interdisciplinary teams; physician payment is through salary or capitation (Canadian Alliance of Community Health Centres). A number of the characteristics of CHCs position them to address the needs of underserved populations. Services through CHCs are characterized by client-centred care, ability to give clients more time, provision of services off-premises where needed, and a commitment to community accountability. A CHC, by definition, is committed to equitable access, and so is more likely to address language and cultural barriers in program design and

management. Some community health centres have adapted programs and services to the needs of all the underserved in their communities, others have developed a population specific approach by specializing in for example, Immigrant Women's Health, or provision of gay-positive health services.

Capitation

A fee for service system has built-in incentives to maximize the number of services, while lacking incentives to increase preventive care. Under a fee for service system, preventive care is delivered in an opportunistic manner in the course of patient visits for other reasons (Hutchinson and Abelson, 1996). This has led to low levels of population coverage for most preventive interventions. At risk, low income and immigrant communities are particularly underserved in this regard (L.L. Roos et al., 1999; Wolishin, 1997). In *capitation* payment systems, the amount of revenue a physician receives is based on an amount paid per patient (capitation fee) regardless of the number of visits. Various formulas may be used to calculate the fee for different practice populations. Capitation payment systems therefore have a built-in incentive to keep a population healthy. They also allow for more flexibility in service delivery and hiring of a greater diversity of health professionals, which allows the potential of a better fit between community needs and service delivery.

However, it is recognized that capitation has the potential to create access problems for at risk or unhealthy individuals (Hurley et al., 1999). This is because the incentives inherent in a system of capitation are to minimize services, provide less expensive services and avoid referral. Patients who may, for a number of reasons, be considered difficult or undesirable to treat (because of a variety of characteristics from limited English / French language ability, to stigmatized behaviours), are likely to face even greater risk of underservice unless specific safeguards are built into any capitation system. It has been observed that under managed care, the most profitable plans are those that avoid caring for sick patients (Kassirer and Angell, 1999). It appears that "geographically based" capitation (which includes all residents of a given area) may pose less risk to underserved populations than "enrollment based" capitation systems which may use a number of strategies to discourage high risk or "difficult"

clients. (Hurley et al., 1999; Closson and Catt, 1996).

Health Transfer to First Nations Communities

Health transfer, described in Section Two, provides a number of potential benefits to First Nations communities, particularly the opportunity to develop and manage programs for their own communities, and address needs in the way the community feels is most appropriate.

However there are also a number of concerns. The key issue is whether the present funding base will be adequate to address the gaps in health services, and as a result health transfer becomes an unloading of responsibility for those who have suffered the greatest inequities (Speck, 1989). Not all programs are eligible for transfer. The process is viewed by some as an attempt of the federal government to rid itself of fiduciary obligations to First Nations peoples, or contravening basic treaty rights to health care. Another issue is that of recruitment of qualified personnel. Workforce supply in remote First Nations Communities has often been a significant challenge, and there is a great need for Aboriginal professionals. Training and other resources are required to ensure that communities have the skills to plan and administer programs as well as deliver services.

Health transfer applies to First Nations communities only; it does not address issues faced by the majority of Aboriginal people. Services to Aboriginal people living off reserve remain a provincial responsibility, and other responses must be found to address the many access barriers experienced by this population.

Diversity Policy

Many of the responses to identified access barriers focus on attempts to improve *client* access. While important, they do not necessarily lead to policy or structural changes which will ensure that all patients get equitable treatment. For example, diversity training may increase the numbers of providers who provide appropriate and sensitive care, but unless policies are implemented which require certain standards of accessibility, providing culturally sensitive care remains "optional". Provision of health funds is not made contingent on ensuring equitable access, based on any other criteria than absence of financial barriers. The onus to identify access barriers falls

largely on the client. Initiatives must be taken to institute mechanisms for ensuring *organizational* access.

One issue is the need for clear policy on access for underserved populations. Such policy should address such issues as: requirement of use of trained interpreters; training and orientation of providers; personnel policies (including hiring policies, and inclusion of cultural competence as performance measure),; and mechanisms for community accountability. There must be strategies in place to review and enforce existing policy.

Partnership/Participation

Organizational access addresses the issue of participation of populations in policy and planning activities. Underserved populations have traditionally been under represented not only among health care providers, but also among academics, researchers, and administrators. Ethnic representation on community and regional health boards is also reported to be poor (Richard and Jagielski, 1999, abstract), and meaningful participation by consumers limited (Vandergang, 1996). One of the first questions in addressing needs for client access is not "*What needs to be done?*", but "*Who should be involved?*"?

The need for joint research initiatives has been recognized by Health Canada through the establishment of community-based research funding programs. These initiatives have included support for capacity building within underserved communities. The Women's Centres of Excellence is one example of a program that requires demonstration of academic/community partnership in research proposals. These initiatives require further development and support.

Establishing partnerships with community organizations, and developing strategies for increased representation at decision-making levels must also be improved in all sectors—academic institutions, health institutions and regional and provincial bodies. Policymaking, research and educational positions are not yet representative of all sectors of the community. Adequate safeguards to ensure this level of participation in the health reform process do not exist.

Section 6: Conclusion

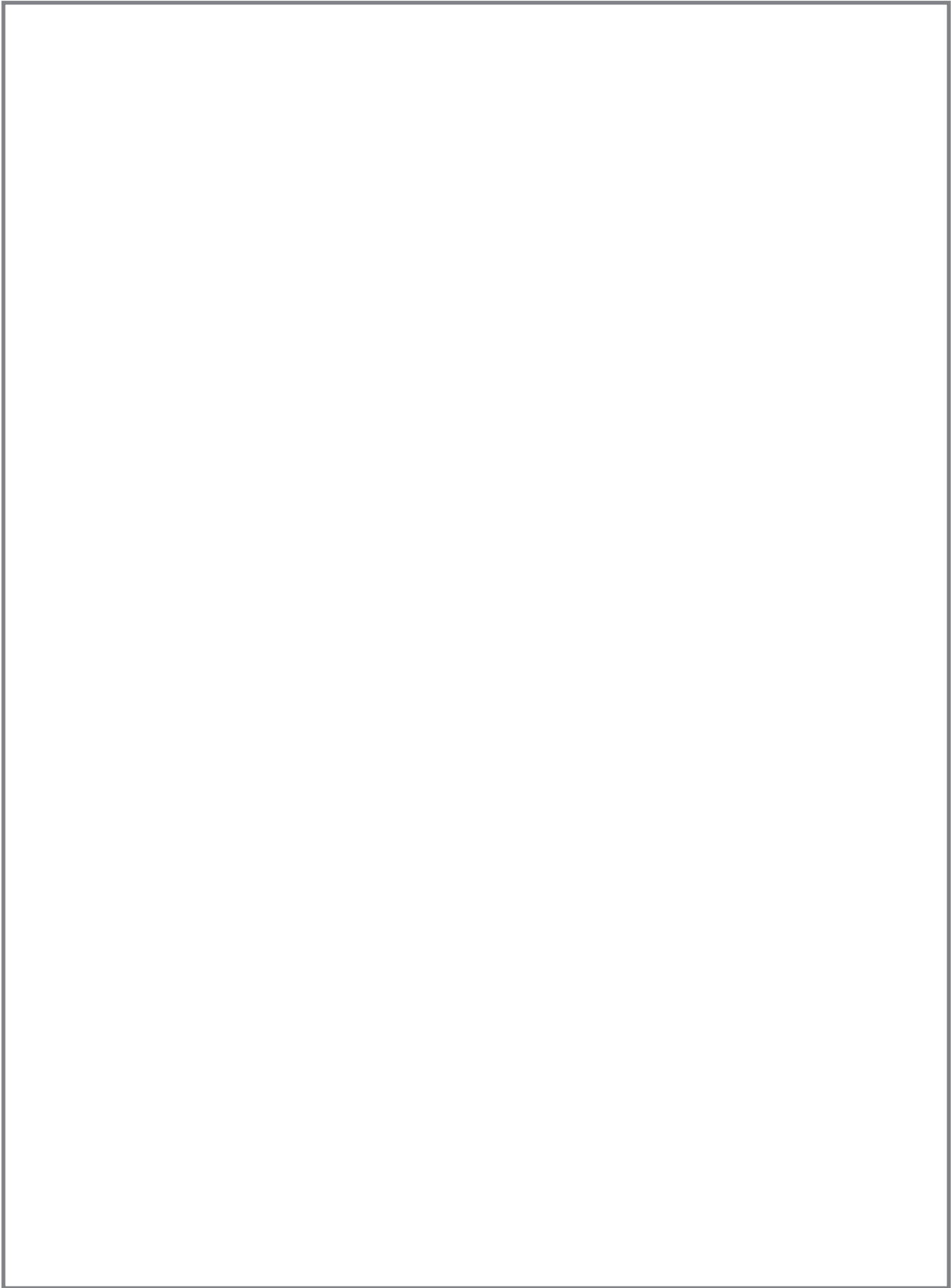
To date, research on access to care in Canada has focused on the removal of financial barriers to care, and to a lesser extent, on geographic issues of distribution and supply. The issue of non-financial barriers to access to care for underserved populations has not been well explored. Concepts are poorly defined and estimates of population size and prevalence of access difficulties are preliminary. More research is needed. This research should be planned and implemented in partnership with the populations affected, and must acknowledge the limitations in existing data and methodology, and the complexity of factors contributing to various forms of underservice.

The provision of universal health insurance has addressed many barriers to care for underserved populations in Canada. There is no evidence of denial of care, and little evidence of differences in treatment related to membership in an underserved population. Many barriers result from difficulties of communication related to language and culture, and from attitudes and knowledge of providers. Limited flexibility of program design, resulting from the historical focus on hospital/physician services, and the structure of funding and payment systems also present barriers. Access to non-insured services is of concern for many in underserved groups as they are generally of lower economic status. Many of the barriers relate to access to prevention, health promotion, and screening programs which implies that underserved populations face important barriers to *health*, not only to *health services*.

In spite of the diversity of barriers experienced by various underserved populations, many of the recommended responses are similar. While there is indication of need for some additional services, what appears to be most important is a change in how services are delivered. Many of the changes identified are anticipated to result in improved service provision for the general population, and have already emerged as priorities through the health reform process. These responses include increased social responsiveness of academic and health institutions, improvements in diversity training for health professionals, development of roles for alternate health providers, and an increased focus on funding and payment strategies which prioritize prevention/ promotion and community based responses.

Particular strategies must be developed to increase the meaningful participation of underserved populations in planning and research activities. This is particularly important now as rapid changes in the health care delivery system create risk for the creation of additional difficulties in access to equitable care for underserved groups.

Changes in health care delivery affect all Canadians, but many people in underserved populations do not fully understand the impact of these changes, and lack resources to negotiate to have their health care needs met.



Glossary

Aboriginal:

all indigenous persons of Canada of North American Indian, Inuit or Metis ancestry, including those in the Indian Register. First Nations population refers to those persons who are registered as Indians under the terms of the "Indian Act" and whose names appear on the Indian Register maintained by the Department of Indian Affairs and Northern Development. Also referred to as "Registered Indians", or "status Indians".

Capitation:

a physician payment system where physician compensation is based on an amount per patient, regardless of the number of visits, rather than a fee for each service provided.

Equitable access:

the provision of health services in a way that provides an equal opportunity for all citizens to achieve maximum health.

Fetal Alcohol Syndrome (FAS):

Set of symptoms and birth defects in a child resulting from the mother's alcohol use during pregnancy. Fetal Alcohol Effect (FAE) describes the situation where only some of the FAS characteristics are present.

Heterosexism:

promotion of superiority of heterosexuality as a social norm.

Homophobia:

fear or hatred of homosexual people.

Immigrants:

people who are, or have been at one time, landed immigrants to Canada" (Statistics Canada). A **landed immigrant** has been granted the right to live in Canada permanently by immigration authorities. **Refugees** who are accepted to Canada are also landed immigrants. **Refugee Claimants** do not have landed immigrant status, they arrive in Canada requesting to be accepted as refugees. **Recent Immigrants** are people who came to Canada within the last five years.

Population health:

the health of a population as measured by health status indicators and influenced by social, economic and physical environments, personal health practices, individual capacity and coping skills, human biology, early childhood development and health services. A population health approach focuses on the interrelated conditions and factors that influence the health of populations over the life course, identifies systematic variations in their patterns of occurrence, and applies the resulting knowledge to develop and implement policies and actions to improve the health and well being of these populations. (Federal Provincial and Territorial Advisory Committee on Population Health, 1999).

Racism:

the belief, with accompanying behaviour, that asserts the inherent superiority of one population group over another, based on biological characteristics. Ethnocentrism refers to the tendency to judge other people and cultures using the customs of our own group as the standard, or see our group or customs as the best.

Self rated health:

how individuals describe their own physical and mental health.

Two - spirit People:

Aboriginal people who are attracted, emotionally and physically, to persons of their own sex, or to persons of both sexes. The term also refers to Aboriginal people who are transgendered.

Underserved Areas:

geographic regions, usually rural and remote, that experience difficulty in recruiting and retaining sufficient numbers of health personnel to meet the needs of the population, or are undersupplied with certain health services.

Underserved Populations:

For the purposes of this paper, underserved populations are understood to include Aboriginal populations, official language minorities, those of alternative sexual orientations (gay, lesbian, bisexual, two-spirited, transgendered) immigrants, refugees, ethnically and/or racially diverse populations, persons with disabilities, the homeless, sex trade workers, and low income segments of the population.

Underservice:

increased likelihood that individuals will, because of their membership in a certain population: experience difficulties in obtaining needed care; receive less, or a lower standard of care; experience differences in treatment by health personnel; receive treatment that does not adequately recognize their needs; or, be less satisfied with health care services.

Unmet health care needs:

a situation where on at least one occasion, the need for health care is experienced but the care was not received (National Population Health Survey).

Visible Minorities:

persons other than Aboriginal peoples who are non-Caucasian in race or non-white in color. (*Employment Equity Act, Canada*).

Appendix A:

Rights to Access to Health Services

The Canadian Charter of Rights and Freedoms

There are two sections of the Canadian Charter of Rights and Freedoms that appear to have applicability to the issue of rights to health care access. Section 15 states that:

“every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical ability.”

This section requires that all Canadians be treated equally. In addition, Section 7, states that:

“Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.”

This section would apply if lack of access could be demonstrated to result in the loss of life, liberty or security (Canadian Bar Association Task Force on Health Care, 1994). A landmark ruling in 1997 by the Supreme Court of Canada suggests that non-financial barriers which result in inequitable standards of care can be challenged. The case of *Eldridge v. British Columbia*, (Attorney General, 1997) represented a challenge to limited language access made by three individuals who were born deaf and preferred to use American Sign Language. Their claim was that British Columbia’s Health Care Services Act violated the provision of the Canadian Charter of Rights and Freedoms; that the lack of provision of sign language interpreters had impaired their capacity to communicate with caregivers and increased the risk of misdiagnosis and ineffective treatment. They asserted that this communication barrier (i.e., the lack of hospital-provided American Sign Language Interpretation Services, which were discontinued in 1990 because of budget cutbacks), caused them to receive a lesser quality of care. The court determined that hospitals were required to provide interpreters for deaf patients,

but left it open to determine whether the failure to provide interpretive services for non-official language speakers would also constitute a violation of the Charter of Rights and Freedoms.

“The possibility that claims for interpretation services might be brought by non-official language speakers, whose claims would proceed on markedly different constitutional terrain than a claim grounded on disability, cannot justify the infringement of the constitutional rights of the deaf. The evidence clearly demonstrates that, as a class, deaf persons receive medical services that are inferior to those received by the hearing population. Given the central place of good health in the quality of life of all persons in our society, the provision of substandard medical services to the deaf necessarily diminishes the overall quality of their lives. The government has simply not demonstrated that this state of affairs must be tolerated in order to achieve the objective of limiting health care expenditures. The government has not made a “reasonable accommodation” of the disability of the three individuals.” (emphasis added). (Eldridge v. British Columbia, (Attorney General), 1997).

Canada Human Rights Act

The purpose of the *Canadian Human Rights Act* is to:

“extend the laws in Canada to give effect, within the purview of matters coming within the legislative authority of Parliament to the principle that all individuals should have an opportunity equal with other individuals to make for themselves the lives that they are able and wish to have and to have their needs accommodated...without being hindered in or prevented from doing so by discriminatory practices based on race, national or ethnic origin, colour, religion, age, sex, sexual orientation, marital status, family status, disability or conviction for an offence for which a pardon has been granted”. (Canadian Human Rights Act).

The Act also states that it is “a discriminatory practice in the provision of goods, services,

facilities or accommodation customarily available to the general public to deny, or deny access to, any such good, service, facility or accommodation to any individual." However, the issue of accessibility standards is addressed directly only for in the case of those having a disability, where "the Governor in Council may prescribe standards of accessibility to services, facilities or premises."

Each province also has its own human rights legislation, and the wording may be different in each. For example, The Manitoba Human Rights Code recognizes that:

"to protect this right it is necessary to restrict unreasonable discrimination against individuals, . . . and to ensure that reasonable accommodation is made for those with special needs" (emphasis added).

Complaints under human rights legislation then appear to be an option for those who believe that they have been discriminated against according to membership in some group. However, the onus of complaint is on the individual; there is no ongoing assessment or enforcement mechanism which monitors rights provisions. What is "reasonable accommodation" to ensure healthcare access has rarely been challenged.

The Canadian Multiculturalism Act

The *Canadian Multiculturalism Act* of 1988 acknowledged multicultural diversity as a fundamental characteristic of Canadian society. It focused on equality of opportunity, participation, contribution and partnership of all Canadians. The Minister of Multiculturalism and Citizenship stated that:

"Multiculturalism...is about ensuring the great institutions of our national life - our policing and justice system, our health and social services, our media and cultural institutions and, not least, government itself - build upon the talents of all our citizens."
(*Multiculturalism and Citizenship Canada, Introduction*).

The act itself also committed the Government of Canada to:

"promote the full and equitable participation of individuals and communities of all origins in the continuing evolution and shaping of all aspects of Canadian society and assist them in the elimination of any barrier to such participation." [3(1)(c)].

However, there is no specific mention of commitment to ensuring equal treatment and protection in access to health and social services.

The passage of the *Canadian Multiculturalism Act* promoted an interest in multicultural health, and beginning in the late 1980's, several initiatives and programs, particularly those focusing on service access, received funding. The Canadian Council on Multicultural Health was formed, along with several provincial chapters. Some provincial governments instituted Advisory Committees focusing on multicultural health issues. Over the following decade however, much of this interest appeared to wane, and concerns regarding cost containment overshadowed that of multiculturalism. More importantly, little policy change within health institutions or practice has been observed.

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Removing Barriers II Keeping Canadian Values in Health Care

Excerpted from the report edited by Ralph Masi, MD

May 2000



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Background

In today's environment, constraints affect the health care of all Canadians. The Canadian hallmarks of health care—universality and accessibility—are increasingly challenged. Reports such as *The Growing Gap: a report on the growing inequality between the rich and poor in Canada*. (Centre for Social Justice, 1999), reflect increasing inequalities in our country. Other Canadian studies, such as the recent one from Centre for Health Evaluation and Outcome Sciences (Wood et al., 1999) have demonstrated that such inequalities result in poorer health status and deaths “from avoidable causes—that is, deaths that could have been prevented through appropriate medical intervention.” Moreover, those who are most vulnerable or marginalized are the same ones likely to be adversely affected by the rapid changes to health care taking place across our country.

There have been few opportunities for health professionals, health agencies and community leaders to collaboratively meet and highlight the impact of proposed health care changes on the more vulnerable or marginalized. Partnerships are needed to preserve and further develop health care that is inclusive of the diversity within our society. The Removing Barriers initiative is intended to focus on the growing inequalities within our country and the threat to Canadian values of universality and accessibility in the midst of rapid changes occurring to our health care system.

The Removing Barriers initiative began in 1997, culminating in a national symposium that brought together community groups, health agencies, professionals and organizations from across Canada. The objectives of the initiative were to promote collaboration, and cooperation and to highlight the health needs of vulnerable or marginalized communities. The first national Symposium, Removing Barriers: Inclusion,

Diversity and Social Justice in Health Care, was held in Toronto, Ontario, June 18-20, 1998. (Further information on the initiative can be obtained from the Web site at www.obstacles.org.) The symposium brought together over 250 people from across the country in an effort to foster national recognition of the common needs and issues of these groups.

The first symposium's content and evaluation attest to its success. They are:

- ◆ Diverse groups from across Canada met to explore health issues of vulnerable or marginalized communities;
- ◆ Recommendations to the health system to integrate and include the needs of vulnerable or marginalized communities;
- ◆ The diverse needs of Canadians within the context of a publically funded health system were delineated.

The symposium was truly a national initiative, providing an opportunity for national dialogue, understanding and approach to the health care issues of vulnerable or marginalized populations across the country. Despite its accomplishments, the symposium could only begin the process required to remove barriers. Follow-up was necessary to develop and strengthen national cohesion and understanding further. The 1998 symposium evaluations clearly recommended a future symposium.

Subsequent to the 1998 Removing Barriers Symposium, the health system has been struck with new challenges.

- ◆ There continues to be an increasing disparity between higher and lower socio-economic groups across the country.
- ◆ The Canadian health care system is under increasing pressure to undergo health

reforms in each of the provinces. Unless constant attention is placed on the issues of inclusion and diversity, it is likely that we will move closer to a two-tier system.

- ◆ The federal government is working to establish a national social and health accord. Interprovincial dialogue is required to identify specific and common needs and issues among the provinces, especially with specific reference to those who suffer from the greatest health inequities—lower socio-economic, vulnerable or marginalized groups. The existing barriers of these groups

must be addressed in both the social support and health care services systems.

Provincial recognition of the issues of inclusion, diversity and social justice that have gone into the development of the Canadian health system is essential to help maintain the principles of the *Canada Health Act*. The objective and theme of Removing Barriers II was to address these issues.

Process

Two separate but integrated components were undertaken as the continuation of the Removing Barriers initiative progressed.

Regional Workshops

In conjunction with the Canadian Council on Multicultural health (CCMH), each health region was invited to participate in a regional workshop on the theme of inclusion, diversity and social justice. The workshops served to secure involvement of local agencies, organizations and health professionals to:

- ◆ Contribute to the process of building national understanding, cooperation and coordination of issues by identifying their provincial issues.
- ◆ Promote and encourage participation in the initiative locally.

National Symposium

The Removing Barriers II National Symposium was held in Vancouver, British Columbia in May 2000. The theme—Keeping Canadian Values in Health Care—focused on the principles of the *Canada Health Act*: Universality, Accessibility, Public Administration, Comprehensiveness and Portability. By exploring these principles in the context of the country's current needs, the intent was to build on the Canadian health system access and ensure its continuity into the new millennium.

The objectives of the Removing Barriers II Symposium were to:

- ◆ Build on the success of the 1998 national symposium, Removing Barriers: Inclusion, Diversity and Social Justice in Health.
- ◆ To unite the provincial initiatives into a national perspective.
- ◆ To elicit issues that merit further attention.
- ◆ To share successful initiatives that address inclusion, diversity, social justice in health care, and encourage modeling.

Two specific actions were the direct result of the symposium: the Declaration on the Values in health Care in Canada; and the request to the federal government for the establishment of a working group on diversity, inclusion and social justice. The declaration statement was developed through discussion in plenary sessions which concluded each day's activities. The draft statement was circulated to participants for final review via the Web site. The declaration statement represents an overview of priority issues that need to be addressed and directions to be taken.

These are just beginning steps in a rapidly changing system that is increasing health inequalities in our country. Undoubtedly there is more to be done. Without such attention, marginalization in health care will increase in our country as well as the disparities. The proceedings and follow-up are a united effort to help address such issues.

Conclusion

Successful change requires time and continuity. The Removing Barriers initiative will need to build on the momentum created. What is needed now is an opportunity to further strengthen those beginnings, and to afford greater opportunities for participation in health care discussions.

A stronger voice is needed in health reforms for the vulnerable and marginalized. Without this voice we risk losing the hallmarks of a compassionate health system that has helped ensure the broad success of the Canada health system: a compassion and inclusiveness that has become an integral component of the Canadian identity.

Ralph Masi
Editor and Co-Chair, Removing Barriers II Committee

Vancouver 2000 Declaration on Values in Health Care in Canada

Canada's health care system is one of the most respected in the world. Clear values, visionary policies and specific legislation provide the safeguards. The Charter of Human Rights and Freedoms and the *Multiculturalism Act* helped create a society in which remarkably diverse people live, work, and interact together in harmony. The *Canada Health Act* helps maintain the system that receives international recognition as one of the best in the world.

Our national commitment to these Acts has brought broad social benefits to all Canadians. Inclusion and diversity are now integral parts of the continuing growth in all sectors of society but despite our success, there is growing evidence of inequality, and there are clear signs of erosion in our commitment. Failure to address this challenge will lead to increased marginalization.

Maintenance and development of health and well-being across all levels of society requires a renewed commitment to basic social justice and equity for all; these are integral to development, funding, organization and actual delivery of all health care. In addition, effective health care must include health promotion and disease prevention.

Diversity and inclusion must be hallmarks of any attempt to renew our efforts; this is the only way to ensure effective and long-lasting development.

THEREFORE, we of the Removing Barriers Initiative call upon federal, provincial, territorial, and regional governments as well as people from all walks of life to reduce disparities in health by committing to the following priorities.

Inclusivity

A systematic and integrated approach including governance and policy must be developed for *all* people of Canada that recognizes gender and gender identity, sexual orientation, religion, socio-economic status, physical disabilities, mental health status, ethnoracial background, or other cultural or physical characteristics. There must be the same commitment to the full continuum of care as promised to all through the *Canada Health Act*. Priority should be given for the development of a systematic and integrated approach for the homeless and those lacking documentation or identification.

Accessibility

Accessibility to health services must be promoted by adapting and situating health care services close to the communities for which they are extended. Explicit standards for inclusivity, employment equity, cultural competency and professional health care interpretation, are needed to reflect this commitment.

Networking, Collaboration and Cooperation

Opportunities must be provided for networking, collaboration and cooperation between health professionals and their communities, and all stakeholders across the country must work together towards the recognition of diversity and the implementation of inclusion.

Health Disciplines Education

Education in all the health disciplines must include mandatory and evaluated content for the development of knowledge, attitudes, skills and judgement appropriate to the needs and care of vulnerable or marginalized communities.

Education programs in all of the health disciplines should also encourage representation from individuals from a broad diversity of backgrounds; financial hardship should not be a barrier to entrance to any discipline.

On-going Development

National professional community and health organizations must take on leadership roles to advocate health care for vulnerable or marginalized communities. Research is needed to support policies, programs and practice to meet the needs of our diverse society.

Together, we are Canada!

Planning

The Next Steps

To work toward the commitment of all people of Canada to recognize diversity and to implement inclusion in health care, we recommend the following:

1. A national working group be struck to provide advice, guidance and monitor progress to national, provincial and territorial governments on inclusion and diversity in health. The national working group should include representation from government, health organizations and agencies, consumers, and health professionals.
2. Financial and human resources be committed to promoting inclusion and diversity within the health care system at all levels of government. The committed funds should afford opportunities for education and the development of resources to assist health organizations, agencies and professionals to respond to the issues of inclusion and diversity. Funded positions should be established for resource people in both planning and delivery of health care services.
3. A task force be commissioned to report on health inequalities in the country, and to advise on specific measures that could be implemented within current resources to help reduce such inequalities.
4. Cutbacks to health services be monitored for increased costs that arise due to increased institutionalization or illnesses resulting from the loss of social or health promotion/disease prevention initiatives.
5. The development of cultural competency standards for health care, including practice standards, administration, policy, education, delivery, and evaluation considerations.
6. Health Canada create a Web site for information on disparities in health care, with links to other related Web sites and resources including standards, training, guidelines for providers and key contacts from different communities across the country.

Copies of the full document are available on the Removing Barriers Web site at www.obstacles.org. or from Suite 406, 1017 Wilson Ave., Toronto, ON, M3K 1Z1

Part II Language and Barriers to Health Care

Document 1

Summary Report — Symposium on Interpreting in a Health Care Setting

*Prepared by: Luc Rochefort
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Language Barriers in Access to Health Care

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Summary Report

Symposium on Interpreting in a Health Care Setting

*November 24, 2000
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*Prepared by Luc Rochefort
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Summary

The symposium, which took place on November 24, 2000, was attended by several members of health care institutions and professional orders. The purpose of the meeting was to examine the issues linked to interpreting in a social setting and to strengthen ties between the various players concerned. The guest speaker was Ms. Sarah Bowen, who drew from the paper, *The Methodological and Policy Aspects of Assessing Interpretation and Language Access in a Medical Setting*.

There is significant cultural, ethnic and linguistic diversity in Canada. In fact, an estimated 2% of inhabitants speak neither official language, be they hearing impaired, indigenous persons or immigrants. Language and cultural barriers have a major impact on the accessibility and quality of health care services. They can result, among other things, in isolating individuals, mistaken diagnoses and inappropriate treatment. They are also manifested in patients' reduced understanding and observance of treatment, poor use of resources and, finally, increased costs.

One solution to ensure equal services for all is to hire interpreters to facilitate communication between patients and care providers. However, the quality of the interpreter also has an influence on the quality of care. That is why institutions like the Regional Office of Health and Social Services in Montreal Centre foresee a demand for trained interpreters, professional interpreters who have received proper training. In fact, the use of untrained interpreters (volunteers, family members or friends of the patient, or bilingual employees of the institution) entails too high a risk of misunderstanding, interference, forgetfulness, change of meaning, and breach of confidentiality. These risks have an impact on the quality of care.

However, accessibility is still mainly a financial issue. Even though the Supreme Court recognizes effective communication as an integral part of medical services, there is no legislation stipulating who is responsible for paying for interpreting services. Canadian and American studies alike

show that language barriers generate additional costs for the health care system. These costs are linked to under-utilization of preventive and primary care programs, higher hospitalization rates and more frequent emergency-room visits due to delayed treatment. Ms. Bowen identified four types of costs: immediate costs (more medical tests); longer-term costs (worse health); costs to patients and their families (loss of time, loss of wages, premature death); and finally, costs in terms of other government-guaranteed services (education and justice).

Symposium participants identified some courses of action and thought. First, there was the importance of establishing training and certification criteria for interpreters, and the need to train care providers to work effectively with interpreters. Second, given the lack of legislation, it would be wise to consider formulating national standards. Lobbying on interpreter certification, on mandatory use of trained interpreters and on funding interpreting services could begin. Third, cooperation among associations should take the form of pressure to raise decision-makers' awareness of the importance of interpreting and the need to free up funds for research in this area. In fact, there is a notable lack of data on the issue. The research could look at costs, the various groups likely to benefit from interpretation services, the complex nature of the situation, the impact of nonexistent services, etc.

The participants' objectives at this meeting were to increase the visibility of interpreters' role, to raise public awareness and consciousness on the part of organizations and institutions with regard to the advantages of professional interpreting services. *The Critical Link Canada* was seen as the ideal agency to coordinate funding and dissemination of this nationwide effort in the short term. The national impact of this initiative will be examined at another meeting in the coming year.

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Symposium Objectives

The objectives of the November 24, 2000, symposium were to :

- ◆ improve interpreting services for users
- ◆ better understand the issues involved
- ◆ channel the resources needed for national lobbying in the area of interpreting, and

- ◆ strengthen ties among the various organizations and institutions participating in the symposium.

Members of health care institutions and organizations, as well as members of professional orders were invited to discuss the topic. (Guests are listed in the Appendix.)

Background

Access to health care services on the part of allophone, indigenous and hearing-impaired communities is still a real issue in Canada. In fact, there are certain barriers to accessibility. Jalbert¹, Gravel and Battaglini² identify, among others, objective difficulties (economic, geographic, language-related and administrative), lack of familiarity with available resources, language and communication problems, and cultural factors.

The *Canada Health Act* sets out five criteria for the equality and quality of services for all Canadian residents and citizens: comprehensiveness, universality, public management, transferability and accessibility. In this respect, interpreting services are extremely important, since they make communication possible during the care episode. However, despite the importance of the interpreter's role, there are no regulations governing interpreting services from one institution to another, let alone across the nation.

Interpreters act as intermediaries in the health care network. The flow of information between interlocutors, which enables proper diagnosis and treatment, is in the hands of interpreters. As such, and as an instrument that facilitates communication between health care users and providers, interpreters become an ideal tool for social integration. Their work contains the notion of assistance, right alongside health care professionals (although their roles differ considerably). Interpreters are therefore an essential part of care. But what do we mean by *interpreter*?

The term *interpreter* takes on a number of meanings within the health and social services system. It covers both trained and untrained interpreters. Trained interpreters are professionals who have taken interpreting courses or tests that establish their skill. Untrained interpreters are volunteers—patients' friends or family members, bilingual employees of the institution, or community volunteers. Impartiality, confidentiality and accuracy of information are all part of trained interpreters' rules.

However, translating is not a simple act, even for trained interpreters. It is the passage from one code to another, and becomes part of a relationship, sometimes affecting the intimacy of said relationship. In this respect, using an interpreter changes some aspects of care providers' practice.

When a trained interpreter is used, this relationship is more neutral. When the interpreter is untrained, he or she is involved in a relationship with the client — a relationship that is difficult to put aside during communication. When interpreting the discourse between the care provider and the patient, the interpreter has an influence on the way communication takes place and on the very content of the intervention.

Interpreting within my organization takes place with the help of clients' family members. It usually results in word-for-word translation of the conversation between doctor and client. This situation creates significant problems. For example, one client came to emergency because of nausea (mal au cœur) translated as pain in the heart. They sent for the cardiologist!³

In fact, untrained interpreting is fraught with potential problems that risk depriving users of effective communication with care providers. That is why institutions such as the Regional Office of Health and Social Services in Montreal Centre prefer to use trained interpreters and recommend the use of trained interpreters by the institutions within its jurisdiction.

The Montreal Children's Hospital receives 3 500 interpreting service requests a year. Before, multilingual employees acted as untrained interpreters. Now, employees receive training and acquire experience in the field. Those with the Regional Board's Interpreters Bank receive more complete training. Untrained interpreters are rarely appropriate in terms of professionalism, ethics and accessibility.

Language Barriers: Impact upon the Accessibility of Health Care Services

The following is a summary of the presentation by Sarah Bowen⁴. Examples, quotes and/or comments from symposium participants have been included in italics.

Introduction

When we look at Canada's cultural, ethnic and linguistic diversity, we understand the need to improve the accessibility of services for immigrants and refugees, indigenous persons and the hearing impaired. In fact, lack of communication has major consequences for individuals: isolation, imprecise and fragmented answers, poor use of resources and cultural bias. Although studies show that these groups experience roughly the same problems with the health care network, the services that give them access to the system are generally developed piecemeal.

According to Ms. Bowen, 17% of the country's immigrants have a mother tongue other than English or French. Ten percent of immigrants use a non-official language at home. Among the indigenous population, 25% speak neither of Canada's official languages. In fact, 2% of Canada's entire population are unable to communicate in French or English. These figures are expected to increase over the next few years. This makes equitable access a major issue in terms of accessibility and quality of care.

There are two potential solutions. The first is for institutions to increase the number of care providers who speak several languages, in the aim of improving and facilitating communication during health care encounters. However, this situation is considered a temporary solution, since it involves greater availability on the part of care providers, who must be freed from their tasks in order to perform interpreting duties elsewhere. The other solution is to set up professional interpreting services.

Access to Services

Distorted communication between users and care providers can generate risks in terms of failure to communicate, mistaken diagnosis, inappropriate treatment, reduced understanding and poor observance of prescribed treatment on the part of the patient, clinical ineffectiveness, lower satisfaction rates on the part of care providers and users, consequences attributable to professional malpractice, and death.⁵ Communication differences linked to culture, beliefs and social status, added to language barriers, can be the direct cause of poor communication and inadequate treatment.

The Concept of Accessibility

Ms. Bowen put forth the concept of *equitable access*, which involves providing health care services in such a way that gives all citizens equal access, so that they can achieve optimum health.

Equitable access is compromised by language barriers, among other things. These barriers furthermore lead to mistaken diagnosis, inappropriate treatment, confidentiality problems, information problems, misunderstandings between care providers and users, exclusion from research and problems in terms of the right of access to health care.

These barriers could be overcome by setting up interpreting services that draw on the skills of trained interpreters. However, the major problem with regard to the accessibility of services remains a financial one. If users must pay interpreter's costs, what will happen when institutions tell clients that they must find their own interpreters? *Equitable access* implies that interpreting costs not be charged to patients.

The Canada Health Act

According to the *Canada Health Act*, "...the primary objective of Canadian health care policy is to protect, promote and restore the physical and emotional well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers." It should be noted that the Legislator did not see fit to define the notions of "reasonable" or "access". Furthermore, the concept of reasonable access is most often interpreted as the lack of explicit financial barriers. The meaning here is therefore far removed from language and cultural barriers.

However, in a decision handed down in 1997, the Supreme Court of Canada ruled that hospitals were obligated to provide interpreters to their deaf patients (*Eldridge v. British Columbia*). The highest court of the land did not, however, address the issue of whether the failure to provide interpreting services to persons who do not speak either of the official languages also constituted a violation of the Charter of Rights and Freedoms.⁶ The Supreme Court nevertheless recognized effective communication as an integral part of providing medical care, and that lack of such communication would result in below-standard care. These principles can also be applied in the case of other persons who speak a non-official language.

Issues Linked to the Different Types of Interpreters

Several studies reveal that there is a higher risk of poor communication when using the services of untrained interpreters, which can be very dangerous in a medical setting, as illustrated in the following comment:

*The error rate of untrained interpreters (including friends and family members) is so high that, in certain circumstances, it is more dangerous to use them than to use no interpreting services at all. The reason being that they give a false sense of security to the client and the care provider, who think that what they are saying is being transmitted word-for-word.*⁷

Bruce Downing, from the University of Minnesota, addresses these risks. Interpreters who do not have the required skills become a barrier to communication because they may:

- ◆ fail to understand the care provider's questions;
- ◆ not be familiar with technical terms and must continually request additional explanations;
- ◆ translate ideas and words incorrectly;
- ◆ answer questions for the client;
- ◆ express personal opinions or breach confidentiality;
- ◆ not be able to interpret the client's response;
- ◆ seriously interfere in the discussion by adding, forgetting or changing the meaning of information;
- ◆ lose track of the conversation.

This was further confirmed by symposium participants:

If the interpreters are not comfortable in one of the two languages, they become more of a distraction than a help.

I work in psychiatry at St. Mary's Hospital. We use a bank of untrained interpreters for a number of reasons, probably due to the time it takes to obtain the services of trained interpreters. In fact, it is more a question of financing. The problem we are currently facing is bias on the part of the interpreters we use: they judge, filter and give a poor interpretation.

A number of issues add to the trained-untrained interpreter dichotomy.

- ◆ When is the presence of an interpreter necessary? Upon the user's request? If possible, at each visit? Upon request by the care provider when he or she notes that communication is difficult? When communication in general could benefit?
- ◆ The patient needs an interpreter, but how does one communicate that need to him or her?
- ◆ Who is responsible for setting up an interpreting system? Who is responsible for funding and operating the system?

The Characteristics of Trained Interpreters

Trained interpreters are chosen on the basis of their bilingualism, their knowledge of the two cultures involved, and are generally trained to:

- ◆ know the terms and subjects in relation to which they are asked to interpret;
- ◆ know the specialized terminology in both languages;

- ◆ develop the qualities needed to be a skilled interpreter;
- ◆ observe professional ethics and maintain confidentiality;

Training is essential to guarantee the professionalism of interpreters, who become mediators and promote understanding in tripartite relationships. Furthermore, the more care providers work with trained interpreters, the more they trust these interpreters, thus facilitating the care providers' interventions.

Interpreting programs have become available at the university and college level in the last few years. Generally, certification takes place within the institution that uses the interpreters' services.

In addition to training and skill, there is the issue of interpreters' salaries and status.

Despite their specialized training, the sign language interpreters within our associations have a hard time getting hired. We should look at the opportunities opened up by technology in the form of video conferencing.

The majority of interpreters at the Multicultural Community Health Centre undergo a training program. Interpreters in the Toronto area manage to make a living from their profession.

The Consequences of Language Barriers

Numerous studies show that language barriers entail additional costs for the health care system at the user end:

- ◆ poor use of preventive and primary care programs;
- ◆ less frequent use of cancer screening services;
- ◆ greater probability of hospital admissions and emergency-room visits.

A study conducted in 1999⁹ showed that language barriers increased the average cost of doctor's visits by over \$38 in test charges due to miscommunication that led to mistaken diagnoses, inadequate tests and longer visits. The study also showed that, in the United States, allophones wait an average of over thirty minutes more a day in emergency rooms....

Health care research findings have associated language barriers with:

- ◆ a higher risk of mistaken diagnoses;
- ◆ problems with the quality of care, noted by patients and care providers;
- ◆ discrepancies with regard to prescriptions (cancer, pain, general);
- ◆ an increase in invasive procedures;
- ◆ less effective symptom management in palliative care.

Ms. Bowen cited an American study in which Hispanic groups were prescribed less pain medication due to language barriers. The study states that care providers' perception of the Hispanic groups varied according to whether or not they spoke English. Unilingual Spanish speakers were lumped together with foreigners, rather than being recognized as American citizens. Allophones in general are subject to preconceptions on the part of researchers and care providers alike, thus creating a bias in research results.

Existing research establishes a correlation between patients' degree of satisfaction, the outcome of the treatment received and their recourse to lawsuits against care providers. Several studies have documented a decrease in satisfaction on the part of patients who have trouble communicating,^{10 11 12 13} as well as their reticence to return for further treatment.¹⁴

In Canada, illiteracy in French and English has also been connected to higher hospitalization rates and a greater number of prescription errors, as well as a lower probability that the patient will follow instructions once discharged from hospital.^{15 16}

Patients' failure to conform to medical treatment is due to misunderstandings between the doctor and the client at the level of diagnosis, treatment and instructions contained in the prescription. Resulting medication errors can even reduce clients' willingness to consult the doctor. It goes without saying that clients' satisfaction rates are also affected.

Fallout (costs)

While it is difficult to assess the cost of interpreting services, it is also a complex task to put a figure on the financial repercussions of not having such services. Researchers stand to benefit by including the following points in upcoming studies:

Immediate Costs Linked to Each Contact with the Health Care System

These costs include the time of the doctor, receptionist, interpreter and other health or community support staff, as well as the cost of medical tests, prescribed medication, and cancelled or missed appointments. It is also important to take into account the cost of emergency-room visits due to treatment not provided in time.

Longer-term Costs of all Contacts with the Health Care System

The repercussions of mistaken diagnoses, delayed access to services and poor treatment execution on the part of patients are not always immediately apparent. In order to be valid, cost measurements should consider the impact of longer-term effects, such as changes in the way services are used, the deterioration of overall health, and the tendency to

depart from the therapy plan. Finally, the consequences of excluding this clientele from research protocols must also be taken into account.

Costs to Patients and their Families

The costs to patients and their families are rarely examined, be it in terms of lost time, anxiety, loss of wages (and perhaps even of their job), avoidable pain and suffering, deterioration of their state of health or premature death.

In addition to direct costs to patients' health, the impact on family members and society as a whole must be examined.

Costs to other Components of the Health Care Network, the Justice System and the Education System

The health of the population has an important influence on the cost of other government-guaranteed services. Poorer treatment results generate costs not only for the health care system itself, but also for the economy, families and the social environment. In the context of greater awareness of the complex interconnection of health factors, these costs must be taken into account.

Some Courses of Thought and Action

Education

The importance of defining training and certification criteria stood out in the group's reflections.

The Children's & Women's Health Centre of British Columbia uses trained and untrained interpreters, as well as bilingual members of the team. We do not yet have the appropriate, concrete means to evaluate interpreters' skills.

However, interpreters are not always available in regional settings:

The assistance program for new Canadians trains its interpreters. The problem is finding skilled interpreters in a small community like the Sherbrooke region, and to train the care providers with whom they work.

When the refugees came from Kosovo, we didn't really have interpreters.

Health professionals must also be trained on the importance of interpreters, on cooperating with them and work methods to improve cooperation between care providers and interpreters.

It is also essential to train care providers to create a better relationship with interpreters.

It would also be a good idea to take advantage of conferences as a forum to discuss the issues linked to interpreting and the organization of services. This would improve recognition of the interpreting profession by peers and care providers, who do not always see the advantages of using trained interpreters. Conferences would raise participants' awareness of the potential impact of cooperation between care providers and interpreters.

Some documents that deal with crosscultural health issues, such as the Ontario Nurses' Guide, could be distributed more widely.

Organizational Policies

There are no concrete laws or guidelines governing interpreting services. While it is possible for institutions to set up criteria that must be followed, there is no national standard. Lobbying must be initiated not only by the

communities that benefit from interpreting services, but also by health care institutions and professionals.

National standards must be established. Recognition of the interpreter's profession must be justified by training, status certification and policies that provide real recognition within the health care network. It is necessary to find new avenues to promote interpreters' status via Canadian lobbying. Furthermore, the Royal College of Physicians and Surgeons of Canada is organizing the PROMED project aimed at improving doctor-client communication. Lobbying efforts should be made in the same direction. In striving for excellence, one must first strive for quality.

It is essential to use interpreters if we want to guarantee the right to access to health care. The problem must be addressed at the national level.

Funding and Paying for Services

Canadian legislation is not very clear about the obligation of health care institutions to provide or pay for professional interpreting services for their clientele.

In the early seventies, the University of Toronto offered a two-year diploma in interpreting. The lack of jobs in that area forced the university to cut the program. There is no specific law in Canada, and no concrete guidelines with regard to interpreting services.

For this reason, public institutions use trained and untrained interpreters, as they see fit.

The Institut universitaire de gériatrie de Montréal uses a bank of volunteers for interpreting services. We also use family members and bilingual staff to act as interpreters.

At the Grace Health Center for Children, Women & Families, we have certified interpreters who have been trained at the cultural and language level.

In Quebec, the Ministry of Health and Social Services and the regional boards finance interpreters' banks, and public institutions pay for interpreting services on demand. However,

regardless of the province, financing remains a problem.

Theoretically, in British Columbia, access to interpreting services is available to the population upon request. The problem lies with financing the service and paying interpreters. There has to be a proven increase demands for service in order to obtain funds.

For their part, private clinics rarely use trained interpreters.

Research on potential lawsuits would make it easier to measure risk management, which could eventually lead to the spread of interpreting services.

Cooperation among Associations

Members must increase pressure on their representatives to make leaders aware of the need for interpreting services. Interpreters' contribution to improving communication with users and providing better care should be an integral part of associations' ethical principles.

Furthermore, health care professional associations must agree on the future of interpreters, and put pressure on institutions and governments to free up research grants and adequate funding for interpreting services. Coordination among Canada's various organizations could take place under the aegis of an association such as the Canadian Deafness Research and Training Institute or Critical Link Canada.

Research

There is a notable lack of data that could be used to justify setting up interpreting services. The Regional Office of Health and Social Services in Montreal Centre is awaiting statistics on users' mother tongues and the percentage of allophones who attend CLSCs. It will then be possible to draw a correlation between this percentage and the total population in each area, and perform a better needs assessment. Organizations and

institutions must record at reception the clients requiring the presence of an interpreter. A number of research projects could be carried out to determine the cost of establishing services, the various groups likely to benefit from the service, the complex nature of the situation, the cultural aspect of communication in a health care setting, etc.

In addition to the costs outlined in Ms. Bowen's presentation, the long-term economic repercussions could be the object of research. In order to achieve this, national lobbying should take place to free up funds for research on interpreting services and their impact on the health care network. Fundraising should not be limited to the federal or provincial government; university institutions and professional associations should also be targeted.

The following priorities stand out in the synthesis of Ms. Bowen's text:

- ◆ an analysis of Canadian approaches aimed at setting up applicable standards for health care institutions. In the United States, major initiatives are currently underway to define standards with regard to cultural skill, including access in terms of language, but they are part of U.S. legislation, regulations and standards. Initiatives in Canada must be supported in order to continue;
- ◆ a more detailed analysis should be carried out on the issue of language access rights in Canada;
- ◆ it is necessary to establish guidelines for researchers regarding the complexity of research in this area;
- ◆ finally, funding for research projects should be increased.

Conclusion

Symposium participants gave themselves the mandate to strengthen the accessibility of interpreting services at the provincial and national levels. Participants committed themselves to pursuing national objectives such as increasing the visibility of interpreters' role, and raising the awareness of the public, organizations and institutions with regard to interpreting services.

Potential actions include placing pressure on institutions, equipping clients to become their own spokespersons, and using the necessary publicity tools.

Critical Link Canada— Un maillon essentiel Canada was chosen as the ideal organization to coordinate funding and dissemination of this national initiative in the short term.

The courses of thought and action proposed at the meeting pave the way for a more in-depth examination of the issue.

Critical Link – Un maillon essentiel

Created in 1992, *The Critical Link* was the forum for organizing the first international conference on community interpreting. Via its Web site, www.criticallink.org, this organization aims to connect interpreters throughout Canada and around the world. Sharing thoughts, issues and

research on interpreting in a social setting enriches the debate in this field.

The Conference: Critical Link 3

The 3rd International Conference on Social Interpreting will be held in Montreal from May 22 to 26, 2001. The numerous and at times contradictory expectations placed on social interpreters reflect the complexity of this profession. Those attending the conference are invited to address, among other things, interpreters' role, training, skill assessment, the conditions for practice and the organization of the profession.

For more information, visit the Conference's Web site at www.rsss06.gouv.qc.ca/english/colloque/index2.html.

Next Meeting

Following up on the thoughts expressed at this symposium, another meeting shall take place within the year to look at the initiative's national impact. Furthermore, a look back on the *Critical Link 3* international conference could be an opportunity to fine-tune symposium objectives, approaches and results.

List of Participants

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End Notes

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- 3 Comments of a symposium participant. All passages in italics are taken from participants' comments.
- 4 It should be noted that *Language Barriers: Impact upon accessibility of health services*, was presented by Ms. Bowen in English, and touched on the main lines of the document *The Methodological and Policy Aspects of Assessing Language Interpreting Services in a Medical Setting*. Written by Sarah Bowen and Joseph Kaufert. Completed by Annick Lenoir-Achdjian. 2000. Paraphrase from free translation.
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Language Barriers in Access to Health Care

Sarah Bowen, B.A., M.Sc.

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Some sections of this report include excerpts from:

Methodological and Policy Issues in Evaluation of Health Interpreter and Language Access Services (2000) by Sarah Bowen, and Dr. J.M. Kaufert, Department of Community Health Sciences, University of Manitoba, supported by the Multiculturalism Program of the Department of Canadian Heritage.

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Introduction

There is increasing awareness that a number of populations are underserved by the health system in Canada (Federal, Provincial and Territorial Advisory Committee on Population Health, 1999; Bowen, 2000). Those who do not speak one of the official languages are one of these underserved groups. In some circumstances, French speakers living outside Quebec, or English speakers living within Quebec may also face similar difficulties. However, little research has focused on the effects of language barriers on health outcomes, service utilization, patient satisfaction, or overall costs to the health system or to society.

For those who do not speak an official language, lack of access is unlikely to be due only to "language barriers". Those who are not fluent in French or English are also likely to be underserved for other reasons. They may be recent arrivals to Canada, or come from isolated communities; they may face discrimination as Aboriginal people or visible minorities, or be perceived as disabled due to deafness. Cultural beliefs about health and illness, expectations of the health system, and roles of participants in a health encounter may also differ from those of their providers.

Research from a number of disciplines has highlighted the importance of culture to health beliefs and behaviours, and to patterns of communication. Understanding and respecting differences between cultures has been highlighted as a cornerstone of cultural competence. Language can never completely be understood (or addressed) apart from other factors related to culture and ethnicity. Language and culture are inextricably intertwined.

However, while it is simplistic and misleading to assume that all access difficulties arise only from the lack of a shared language, unless there is communication, these alternative understandings will not be revealed. Language is the base, the prerequisite, for further understanding. We are aware that income, gender, socioeconomic level, education, and a variety of other factors, such as sexual orientation or presence of a disability, are also part of an individual's "culture". However, without effective communication, this heterogeneity within each ethnic/cultural group,

and the needs and characteristics of the individual cannot be assessed.

Language has been described as medicine's most essential technology – its principle instrument for conducting its work (Jackson, 1998). It has been observed that without language, the work of a physician and veterinarian would be nearly identical (Clark, 1983). Establishing communication enables all parties in a health encounter to participate in the exploration of the illness or condition, and to determine together what aspects of the "culture" of both patient and provider must be considered in diagnosis and treatment.

In comparison with other health "technologies" however, interventions to facilitate language access (such as interpretation), like general issues in provider-patient communication, have received little research attention (Kaplan et al., 1989).

Purpose and Scope of Report

The purpose of this report is to provide an overview of current research describing the impact of language barriers on health care access and quality, and the role that language access programs can play in addressing these barriers. While the review includes studies done in other countries, the report is designed to provide an analysis of the research evidence from a Canadian perspective, and to assess the implications of findings for the provision of health care in Canada. It provides a brief overview of the emerging issues related to models of service provision, interpreter training and service standards; however the report focuses on assessment of the effects of language barriers on access to health care, and quality of care received. It also examines a number of indirect effects of language barriers within the health system, including the issues of research participation, effect on providers, and health care costs.

It is not within the scope of this report to explore a number of important topics related to the provision of language access services. It does not review the important and substantial body of work on the relationship between language and culture. The

case study literature that provided the basis for more empirical research on the effects of language barriers is under-represented in this report. Also not included are discussions of theories of interpretation, or analyses of different methods of interpretation. An additional limitation of this report is that it does not include much

research that is part of the 'grey' area of unpublished literature. Much of the work done in Canada related to language access programs is found in such reports.

Overview of Issues

Approaches to Addressing Language Access to Health Care

It is generally accepted that there are two basic approaches to addressing barriers to communication that are caused by the lack of a shared language between client and provider. The first is to increase the number of encounters where client and provider share the same language (i.e., the number of "language-congruent" encounters). The second is to provide some form of interpretation.

Increasing Proportion of Same-Language Encounters

Increasing the proportion of encounters within the health system where there is language congruence between provider and patient is often viewed as the ideal response. Many authors believe that providing an interpreter can never be as satisfactory as direct communication, no matter how skilled the interpreter. This results from the desire on the part of both parties for direct, unmediated communication, and the recognition that even the presence of another person in the encounter can affect rapport and the type of information shared.

Increasing the number of language-congruent encounters can be accomplished either by:

- a) Increasing the number of providers who speak other languages, or
- b) Increasing the number of minority language speakers who speak the official language(s) of the country.

Increasing the number of providers who speak other languages

A number of different strategies have been proposed to increase the proportion of health care providers who speak the language of minority language communities.

Employment equity strategies facilitate entry of bilingual providers into the health professions. These strategies may either focus on recruiting members of underserved communities into professional preparation programs (pre-service

initiatives), or on facilitating entry of trained professionals into a variety of positions (post-graduation initiatives). Special "access" programs to facilitate entry of Aboriginal students into health professional training programs, are an example of pre-service initiatives. However, not all members of targeted groups have the presumed language ability. In Canada, for example, a relatively low number of Aboriginal access students speak a First Nations language. Strategies for facilitating licensing of foreign-trained medical graduates are examples of post-graduation initiatives. Neither of these responses has traditionally been pursued in Canada, although since the Royal Commission on Aboriginal Peoples there have been significant initiatives aimed at recruiting and training Aboriginal health professionals.

While this alternative has an important potential for addressing the larger issue of cultural competence within health professions, it cannot by itself fully address all needs for language access:

- ◆ Many Canadian cities have small numbers of individuals from different linguistic and ethnic groups. It is not feasible to offer even primary care to all communities by a provider of the same ethnic or language background.
- ◆ There is great diversity within ethnocultural communities. Placing patients with providers of the same "ethnic" or language background may actually contribute to distrust if the patient and provider are of different political, socioeconomic, religious or regional backgrounds (Lin, 1983). This form of matching may also provide only partial language access where there are differing dialects; and significant differences in health care beliefs and practises related to socioeconomic status or region may be ignored.
- ◆ While minority language communities advocate for provision of services in the patient's first language, the concern has been voiced that community members do not want to be "ghettoized" with a choice of only one or two providers. This problem is particularly significant in small communities.

- ◆ Confidentiality and emotional safety may be of concern when visiting a provider from the patient's own "community", particularly in small or politically divided communities.
- ◆ Initiatives that focus on increasing representation for only one or more professions will not address all needs. For example, initiatives to increase the number of physicians speaking a minority language are inadequate as the sole response, as physician access is only one component of health care. Comprehensive health system access necessitates dealings with many different health care providers (e.g. nurses, health educators, imaging technicians, dentists, physiotherapists, and psychologists).

Another approach to increasing the proportion of shared-language encounters is to increase the fluency of providers in non-official languages through provision of language training. In the United States, some initiatives have been taken to encourage providers to learn the language of minority groups (Prince & Nelson, 1995; Binder et al., 1988; Koff & McGowan, 1999). The effectiveness of this has not been adequately evaluated. However, our understanding of the limitations of interpretation undertaken by interpreters who are not completely bilingual suggests a number of concerns with this approach. Researchers have highlighted the risks of "false fluency" of providers who, having only limited proficiency in a second language, attempt to communicate without the assistance of an interpreter (Flores et al., 2000). In these cases the provider may believe that s/he understands the patient and is communicating questions and instructions clearly, but serious and dangerous miscommunication can occur.

Increasing the number of minority language speakers who speak English or French.

Rather than developing strategies for increasing the number of providers who speak minority languages, it is often argued that the emphasis should be on assisting minority language speakers to learn English or French. This appears to be the main approach in Canada for addressing language access needs of new immigrants. Lack of fluency in an official language is perceived as a time-limited problem that does not require systemic change. It is assumed that immigrants (who are expected to learn English or French,

depending on their province of settlement) will soon be speaking one of the official languages. The number of same language encounters is expected to increase as the newcomer's language proficiency increases. However, second language training and other support services designed to assist newcomers in adapting to Canada are provided for a limited period of time. The same attitude may be expressed regarding Aboriginal languages: as many Aboriginal young people are monolingual in English or French, some suggest that these languages are "dying out", and interpretation services will become less important in the future.

Of course, newcomers generally wish to become independent and to have the same privacy in health interactions valued by all Canadians. Many learn to speak English or French proficiently, and no longer need or use interpreters, even in situations where they are available. It is also true that many Aboriginal people are fluent in an official language.

This response, however, does not address the needs for health care access faced by new arrivals who are considered the group with greatest need (Kinnon, 1999). In addition, the reality is that there are a number of immigrants who do not, even after several years in Canada, speak English or French well. These individuals are more likely to be women with young children, the elderly, the poorly educated, or those suffering traumatic events or psychological disorders (Stevens, 1993b; Jackson, 1998). These same groups have been found to have high levels of unmet need for health services. Recent studies have found that even several years after arrival, a number of newcomers lack the language skills to communicate with their health care providers in English or French. Many more are able to communicate adequately for what they believe are straightforward problems, but are unable to understand more complex disorders or cope with highly stressful health-related events in a second language (Stevens, 1993b; Bowen, 1999). Similar findings have been reported in other countries (Jackson, 1998).

In addition, the argument that the need for language access services will diminish over time fails to address either the current reality of many First Nations and Inuit persons who are not fluent in English or French, or the rights of First Nations and Inuit people to maintain their own languages. While services for Deaf people have often been provided within the context of « disability »-related

access services, many Deaf people identify deafness not as a disability, but as a culture. As such, they wish to preserve both their culture and language (Swanson, 1997; Witte & Kuzel, 2000). Promotion of cochlear implants for Deaf children identifies deafness as a disability, and in attempting to incorporate Deaf children into "mainstream" culture, also aims to increase the number of official language speakers.

Providing Interpretation^a Services

The second major approach to improving language access accepts that there are significant communication barriers between many patients and providers. While individuals (or specific language communities) may gain language fluency, and eventually no longer need interpretation services, it recognizes that there will always be a need for language access services for some members of society. This approach will be the focus of this report.

Interpreter functions may take many forms, and the diversity of program models and interpreter roles creates additional difficulties in designing valid research and evaluation models. First, the person performing the interpreter function may be a family member, a community volunteer, a staff member of a health institution, a bilingual health care provider or a trained professional interpreter. The untrained interpreter's level of proficiency in both the official and minority language may vary, as may his or her knowledge of the subject area for which interpretation is needed. Volunteer or untrained interpreters may or may not have received training, either in the skill of interpreting or in professional ethics. The need to maintain confidentiality and objectivity, emphasized in professional ethical codes of conduct in health interpretation, is seldom recognized by informal interpreters.

Second, both the ideal and performed role of the interpreter may vary. The interpreter may be expected to provide anything from straightforward neutral language interpretation, to cultural interpretation, advocacy, or health educator

functions (Putsch, 1985). This range of service models and interpreter roles, and variation in skill and training, creates significant challenges in establishing standards or comparing research from one program to another. In addition, significant variation can be found between providers in both their awareness of the impact of language barriers and their skill in working with interpreters. This also affects the effectiveness of the interpretation process. The risks of using untrained, informal interpreters, the various roles played by interpreters, and models of interpreter service provision will be discussed in more detail in the following sections.

Stakeholders in Language Access Services

At present, there are many varied and often competing demands within the health care system. On the issue of language access, a number of different stakeholders may assert alternative views on the provision of language services. These stakeholders include health care providers, administrators, government policymakers, human rights bodies, community, advocacy or consumer groups, training institutions, entrepreneurs, and members of First Nations, immigrant and Deaf communities. Some may assume that all stakeholders are concerned about the same thing – the improved health of the client. However, the diversity of stakeholder group interests suggests that they may actually have varying agendas. These may include:

- ◆ meeting funding or legal requirements (as in the United States, where federal funding may be contingent on providing language access services);
- ◆ reducing inappropriate or high cost service utilization;
- ◆ protecting an organization from liability;
- ◆ improving health outcomes for disadvantaged groups; or
- ◆ gathering information to support or justify an existing program.

^a For the purpose of this report, *interpretation* refers to the process by which a spoken or signed message in one language is relayed, with the same meaning, in another language. *Translation* refers to the written conversion of one language into another. Two common forms of interpretation are *simultaneous* interpretation, where the interpretation is delivered nearly instantaneously after the original message. This is the common form of conference interpreting. *Consecutive* interpretation involves interpretation of segments of a conversation, with a lag between the original message and its interpreted form. Interpretation may also be categorized as *proximate*, meaning the interpreter is present in the encounter, or *remote* (e.g. by using telecommunications technology). American Sign Language (ASL) interpretation is most often proximate and simultaneous, while most other health interpretation is consecutive and proximate, although the development of communications technology has increased the availability of remote, and simultaneous interpretation.

These varying agendas in policy and program development drive both expansion and containment of language access services. For example, administrators may favour a narrower evaluation of more circumscribed models of objective interpretation and outcome criteria, and may emphasize costs as the dominant dimension. Health care users and advocacy groups, on the other hand, are more likely to promote a broader evaluation based on rights to access and health outcomes.

Initiatives for Health Reform/Managed Care – Policy initiatives emphasizing "health reform" and "managed care" have as a goal decreasing unnecessary and inappropriate use of the health care system. The impetus for such reform is to contain costs and direct resources more efficiently and effectively. Interpreter services will therefore be expected to receive support if they can be demonstrated to decrease costs. The focus on increased efficiency and cost saving appears to have been a major factor in the increase in research related to the impact of language access in the United States.

Fear of Litigation/Legal Challenges – Fear of malpractice suits and legal sanctions are important factors in stimulating the discussion on interpreter services in the United States. This has not been as important a motivator in Canada, although concern about malpractice is growing, and recent cases successfully argued on the basis of the Canadian Charter of Rights and Freedoms, suggest that legal challenges may become a more important force in the future (Champion, 2000).

Competition Between Health Care Providers – Adoption of managed care in the United States has created a situation where, in order to enrol additional members, specific services are offered to attract certain target groups. This has resulted in some managed care providers targeting patients with limited fluency in English for enrollment in their plans, and including language access services in the package provided to them (Herrera, 1998). One writer states, "Beyond being a culturally sensitive « nice thing to do », providing interpreter services can give a hospital a significant marketing edge" (Larson, 1997:20).

The same forces are not present in Canada's publicly funded system. Some institutions (e.g. faith-based services) have had a traditional relationship of service provision with specific language communities; however this varies by region and by institution. While there is an

expectation that health facilities address the needs of patients within their region, whether the devolution of responsibilities for health care to regional health authorities results in greater responsiveness to the needs of language minorities is yet to be seen.

Technology Development – The development of remote technology for interpreting (such as telephone language lines) has created the opportunity for entrepreneurs to package a simple, easily accessible product, which can be "understood" by health care providers. There is also the potential for innovations in "tele-health" or "tele-medicine" to address language barriers in much the same way as they now address distance barriers, both through the provision of multilingual health information, and possibly by limited use of distance consultation.

Human Rights Legislation – Human rights legislation in Canada provides a framework within which rights can be challenged. However, unlike some other countries, where legislation linking funding to addressing language/cultural barriers has been an important force for change (Perkins & Vera, 1998), this has not yet emerged as a major force in Canada.

The Role of Research Evidence – The emphasis on cost containment within the health care system has increased demands for "evidence-based" decision making. Until recently, there was little research available on the effects of language barriers and language access services to guide policy and program development. Although research is still in the early stages of development, there have been several important studies conducted over the past few years. These studies have provided evidence that language barriers are associated with differences in service utilization, patient health outcomes, patient satisfaction, patient "compliance", participation in health research, protection of patient rights, and patient knowledge of diseases and conditions. The significance of these findings increases when links are made with related research (such as patient/provider communication and literacy in an official language).

The objective of this report is to review this recent research. The environment within which the research is conducted affects the research undertaken, and the responses to it. In the following sections, various cultural assumptions, policy agendas and evaluation traditions will be explored. They have affected the development of

models of research and evaluation, priorities for research and the kind of data collected.

Current Issues and Initiatives

Current Issues in Interpretation

The focus of research to date has been on the question of whether, and to what extent, language barriers (and language access programs) affect patients, providers, and the health care system. In addition, there are four related issues which are currently receiving research attention: defining the interpreter role; establishing the most effective models of service provision; professionalization of the interpreter role (addressing the issues of training, standards and accreditation); and economic evaluation of language barriers and program responses. A brief overview of each of these follows.

Defining the Interpreter Role

There has been a debate for many years about what exactly is meant by "interpretation", how broadly the interpreter's role can be defined, and whether objective language "translation" can (or should) be combined with other roles (such as cultural interpreter, educator, mediator or advocate). This debate has highlighted crucial issues for service provision, and cannot be resolved easily (Downing, 1995).

On the one hand, both providers and patients express concern about an expanded role for language interpreters, which could include functions such as advocacy or cultural mediation. Professionals want direct communication with the client, and are often uneasy with any role other than exact transmission of messages. A number of case studies in the descriptive literature, describing distortions, censoring and influencing by untrained interpreters, make this a legitimate consideration for providers (Marcos, 1979; Downing, 1992). Those requiring the services of an interpreter may also object to the assumption that they require any assistance other than language interpretation, and identify themselves as capable of doing their own "cultural mediation".

On the other hand, many recognize the inherent "power imbalance" that exists within the health care provider/client relationship. They also see the risks that arise through miscommunication not simply because of a lack of fluency in the dominant language, but also due to different

assumptions related to roles, health, and appropriate communication (Putsch, 1985; Stevens, 1993b; Jackson, 1998).

Varying interpreter roles, in different programs and contexts, pose important research challenges. One cannot assume, for example, that the impact of a language/cultural interpreter/advocate will be the same as that of an interpreter who limits his or her role to strict language interpretation (as in remote phone interpretation). In addition, interpreters do not necessarily have equivalent levels of experience. A major limitation of much of the research undertaken to date is that the proficiency level or role of the interpreter is rarely considered and/or controlled for in the research design. More research is needed to determine the effect of various interpreter functions, and the role played by health interpreters.

Models of Service Provision

A related but separate issue is that of models of service provision. The kinds of interpretation services provided to patients may vary considerably. Such services may be provided by:

- ◆ family members or friends of the client,
- ◆ bilingual personnel within the health care system,
- ◆ community language bank volunteers,
- ◆ medical interpreters who are trained and employed by the health institution,
- ◆ paraprofessionals with health, outreach, or educational responsibilities, who include interpretation as part of their role,
- ◆ other programs or services that address language barriers.

As indicated above, many of the current responses to language barriers in the health system in Canada rely on untrained and often unpaid « volunteers ». These responses are not "models" of service, but "make-do" solutions in the absence of a formal, defined service. There is however, consensus among experts in the field that untrained interpreters pose many risks to both the patient and the provider – risks that may be greater in many cases than having no interpreter at all. A recent report of the U.S. Office of Minority Health (1999) observes:

"...The error rate of untrained "interpreters" (including family and friends) is sufficiently high as to make their use more dangerous in some circumstances than no

interpreter at all. This is because it lends a false sense of security to both provider and client that accurate communication is actually taking place."

Determining which model of trained, professional interpretation is most effective in a given situation is not as clear-cut. The diversity of practice settings, variations in the size of populations of non-official language speakers, as well as differences in supports available in specific communities, pose challenges to determining effective and affordable models. The "model" of service provision cannot be isolated easily from the definition of the interpreter role. The objectives of a particular program (whether to provide core "translation" functions, or alternative roles in cultural mediation) will affect both the expectations of the interpreter's role and the model of service provision.

Professionalization of the Interpreter Role

Although reliance on untrained interpreters remains the norm in many Canadian centres, there is currently an emphasis on developing competency standards and performance evaluation tools for interpreters. This reflects a movement toward professionalizing and accrediting health interpreters (Downing, 1997; Ozolins, 1998). Paid interpreters are not always professional interpreters. There is great variation in the quality of training obtained, and the level of skill demonstrated by interpreters in Canada, even when they are employed as interpreters.

In other health professions including medicine (Friedson, 1970; Coburn et al., 1983) and nursing (Olesen & Whittaker, 1968), a process has been documented through which health practitioners have attempted to legitimate and legislate defined relationships with the client. Where professions have succeeded in defining membership (by establishing laws, setting internal standards of practice, and adopting professional codes of ethics), clients and practitioners are able to interact on the basis of defined obligations defining conduct and reciprocity. For example, provincial "medical acts" gave physicians control over prescribing many primary diagnostic and treatment activities. They do this by defining roles, establishing standards of practice and restricting the roles of other professions and alternate practitioners (Coburn et al., 1983).

However, this model of professionalization may not be the most appropriate for developing a "profession" of

health interpretation. This is because professions such as medicine are based on a unique relationship with the client. In contrast, although interpreters may function as private contractors, their role as intermediaries between health professionals and clients makes it difficult to achieve independent professional status based on having a separate relationship with the client. In fact, the advocates most strongly committed to professionalization are often those most likely to resist definitions of the interpreter's role that are characterized by independent power relationships.

Economic Evaluation of Language Barriers and Program Responses

While issues of role definition, models of service provision, and professional standards have been the focus of attention from those working in the field, another issue has also been gaining prominence. With greater awareness of the costs of language barriers, there is increasing interest in undertaking an economic evaluation of interpreter services. However, very little research has been done in this area, and the economic evaluation of health care is itself a newly developing, though expanding, area.

Proponents of improved language access in health care often express concern about economic evaluation, fearing that it may result in avoidance of the issue of rights to service. However, economic evaluation is only one component of decision making, which should also include other forms of evaluation (efficacy, effectiveness and availability) and a review of ethical issues related to service provision. There are also concerns that researchers may define costs and consequences of language barriers too narrowly, resulting in an underestimation of the true societal costs of failure to provide language access.

Current Initiatives

There is increasing awareness in many countries of the importance of communication in the area of health care access and quality of care, and interest in promoting research on the effects of language barriers. For example, the United States has undertaken a review of national standards for culturally and linguistically appropriate health care. These standards explicitly address the clients' right to bilingual staff or interpretation services, access to information in their own language, professional standards for interpreters,

and inclusion of language identifiers in data collection. These standards are based on U.S. legislation and enforcement capabilities, and describe a level of service which is certainly not yet available for minority language speakers in Canada (Office of Minority Health, 1999).

Belgium has made a commitment to a "cultural mediator" model for health interpretation, and is actively promoting and disseminating research (Verrept & Louckx, 1998). In Australia, a public inquiry examined rights to interpreter services in the justice system and in health care (Lawrie, 1999).

In Canada as well, there is renewed interest in the issue of language access to health care. National conferences on community interpretation have been held in Toronto (1995) and Vancouver (1998). Since these conferences, panels, networks and internet interest groups have been exploring issues related to the testing and accreditation of interpreters in Canada, with some provinces (such as Alberta and Quebec) developing more advanced programs. In May of 2001, Canada will be hosting the Third International Critical Links (Interpreting in the Community) Conference.

In 1999, Health Canada published Canadian Research on Immigration and Health (Kinnon, 1999), and research funded through the Metropolis Project is expected to contribute to the knowledge on health access issues. Kinnon noted the lack of research on the effects of health system support on immigrant health, and the associated scope for initiating new research in this area.

A preliminary review, funded by the Department of Canadian Heritage (Bowen & Kaufert, 2000b), identified several critical ethical and methodological issues related to language access research. A Health Canada report, *Access to Health Care for Underserved Populations in Canada*, provided a framework for exploring

barriers to access for a number of populations, including those facing language barriers (Bowen, 2000).

In Canada, few health jurisdictions or institutions have implemented policies requiring that some form of language access service be provided to all patients. Additionally, each of the communities for whom language access is an issue is viewed differently in terms of rights to language access. Services for specific communities have tended to develop in isolation from one another.

A landmark ruling in 1997 by the Supreme Court of Canada determined that hospitals were required to provide interpreters for Deaf patients (*Eldridge vs. British Columbia [Attorney General]*, 1997). This recognition, that effective communication is an integral part of the provision of health services, has focused attention on the rights of other language minorities in the country.

In November 2000, a day-long national symposium, *Communication Barriers: Challenges and Responsibilities of Caregivers and Institutions*, supported by Health Canada, brought together representatives from a number of different areas: health care providers, government representatives, Deaf and immigrant community representatives, and providers of language access services. It explored the implications of language barriers for the health professions, focused attention on the specific issue of health interpretation, and emphasized the need for a coordinated national response to the development of standards, training and certification of interpreters. It also endorsed the need for Canadian research (Rochefort, 2000). Specific interest was expressed in evaluating evidence of the impact of language barriers on health and utilization of health services.

The Canadian Context of Service Provision

Introduction

In many ways, the issues faced in the provision of health services to those who lack proficiency in an official language may appear similar between countries. Certainly, from the perspective of users of health services, many of the difficulties and risks involving communication are the same. In many jurisdictions there is no organized health professional interpretation service. Because the health care system does not take responsibility for ensuring communication between patient and provider, the problem of finding, evaluating, booking and even compensating an interpreter remains the responsibility of the patient.

There is, however, significant variability between health systems, and between countries. While much research and evaluation undertaken in other countries may have important implications for Canadians, every health care system is an expression of "the political culture, the social and moral values, and economic imperatives" of the society it serves (Canadian Bar Association Task Force on Health Care, 1994:1). This section is therefore intended to provide an overview of the context within which health care is delivered in Canada, how issues of access and equity related to health care have been understood, and how research related to language access has developed.

Constituencies Affected by Language Barriers in Health Care

In Canada there are four constituencies who may face barriers to health care due to having a non-official first language^b:

- ◆ First Nations and Inuit communities,
- ◆ Newcomers to Canada (immigrants and refugees),

- ◆ Deaf^c persons, and
- ◆ Depending on location of residence, speakers of official languages (French and English).

Provision of language access services, and rights to such services for each of these constituencies are shaped by a distinct historical, legal and political context. Although many of the issues faced by patients may be the same, there has historically been little joint advocacy or even sharing of expertise between these four language constituencies.

Health Needs of Language Constituencies

There are significant differences in health status and prevalence of disability between the various constituencies. Aboriginal people are recognized to have lower health status than the general Canadian population, as measured by almost every health indicator (Health Canada, 1999). These differences are attributed to widespread and historical inequities. In contrast, newly arrived immigrants are generally healthier than those born in Canada, and have longer life expectancy and disability-free years (Chen, Wilkins & Ng, 1996; Chen, Ng, & Wilkins, 1996). This is often explained by the "healthy immigrant effect": people who emigrate tend to be in better health, are often younger, and are medically screened before being accepted into Canada. Over time, the health status of immigrants tends to become more similar to that of persons born in Canada. While this is often understood to result from the fact that they are exposed to the same environmental factors as the Canadian-born, it may also be because they face additional health risks, such as discrimination (Kinnon, 1999) or reduced access to health services. Among immigrants there are significant differences in health status based on country of origin,

b This report focuses on those who face language barriers due to having a non-official first language. It is also recognized that many official language speakers with low literacy also face 'language barriers', particularly to written material. However this group is not the focus of this report.

c The word deaf, when the d is capitalized, as in *Deaf*, refers to those who belong to the cultural community of Deaf people. Many of these persons are pre-lingually deaf, and while they may learn to read and write English or French, they learn these as second languages. In contrast, the words *deaf*, or deafened (with a lower case "d") refers to lack of hearing. Not all those who are deaf are members of the Deaf community or use sign language, the focus of our discussion here. While persons who are hard of hearing also face communication barriers, this review of the research focuses on barriers faced by Deaf persons.

socio-economic status and education (Dunn & Dyck, 2000). Refugees tend to have lower health status and higher health care needs than other immigrants, and are less likely to speak English or French. There is evidence that Deaf persons also report lower health status (Zazove et al., 1993; McEwan & Anton-Culver, 1988), although one study found that pre-lingually deaf adults were at no greater risk of mortality (Barnett & Franks, 1999).

Similarities and Differences Between Constituencies

Little research has examined the similarities or differences in the effects of language barriers between the four constituencies. In particular, the Deaf community is typically not considered a language minority in the same sense as speakers of other minority languages, although some authors have described the similarities between them (McKewen and Anton-Culver, 1988; Barnett, 1999). Similarities include: limited access to official language information, exclusion from "ambient" sources of information, infrequent encounters with physicians or other health care providers from their own cultural group, and language barriers to appropriate care (Barnett, 1999). One U.S. study compared the self-reported experiences with health communication of 119 immigrants with a grade four to five level of English comprehension, with 22 Deaf persons. The two groups were similar in age and education. Participants were asked a variety of questions about communication with their physicians, as well as demographic information. The authors found no significant differences between the groups in their ability to correctly identify commonly used medical words, or in their assessment of how often they failed to understand their physician or ask clarifying questions. There were, however, significant differences in responses in three areas: deaf participants were more likely to feel their physician did not understand them, and were less likely to attempt to re-explain themselves. They were also less likely to report being able to speak to a physician in their language of fluency (McEwan & Anton-Culver, 1988).

Historical and Cultural Context of Language and Service Provision in Canada

Canada has defined itself as a bilingual, multicultural country. Passage of the Official Languages Act in 1969 entrenched in law the rights of both English and French speakers to a range of services in their first language (Bastarache et al., 1987). However, Francophones living outside of Quebec (and some Anglophones living in Quebec) may also face language barriers to care in their first language, depending on the location of their residence (Martin, 1992). There is no specific legislation mandating provision of language services in other than the two official languages, except for criminal proceedings.

Aboriginal languages have special recognition as protected languages in some regions (Bastarache et al., 1987). Before 1999, Aboriginal languages had special legitimacy in the Northwest Territories, and with the creation of Nunavut, Inuktituk has become an official language of the government. Federal administrative and service delivery systems, such as the First Nations and Inuit Branch of Health Canada, have provided some interpretation services for northern communities, and for some patients requiring tertiary care in urban hospitals. While 80 to 90% of urban Aboriginal people in Eastern Canada speak an official language, a significant proportion of Aboriginal people in Western Canadian cities may lack the functional language capability to communicate in an official language during encounters with the health care system. The needs of urban Aboriginal people were not seen as a priority target population for interpreter services provided by the First Nations and Inuit Branch, although hospital-based programs such as those in Winnipeg, Brandon, Thompson and Regina serve the needs of all Aboriginal peoples who require language access services. This includes a significant number of northern Inuit and First Nations people who come to urban areas for treatment. Increasing sensitivity to the rights of First Nations peoples, increasing self-management of health programs, and lobbying by First Nations political organizations are contributing to greater responsiveness to language/cultural access in health care for Aboriginal peoples. This creates a very different context for service provision than for immigrant minority language speakers.

Most of the Deaf community in Canada uses American Sign Language (ASL) for

communication, although French Sign Language (LSQ) is also used. Although the Deaf community has differentiated its advocacy for recognition of Deaf culture from other disabling conditions, provision of sign language interpretation services for the Deaf community has followed a different path – that of advocacy for disability rights. These rights are more clearly specified in Canadian Human Rights legislation; and a landmark Supreme Court ruling (*Eldridge v British Columbia [Attorney General]*, 1997), determined that failure to provide a sign interpreter when necessary for effective communication in delivery of health care services constituted a violation of the Canadian Charter of Rights and Freedoms (Stradiatto, 1998).

“Immigrant” Languages

Language barriers faced by immigrants in Canada are generally considered to be “newcomer” issues, rather than minority issues, as in some countries such as the United States. While “minority” issues are more likely understood in terms of rights of marginalized or racially/ ethnically different groups, “newcomer” issues are seen to be time-limited, related more to the adaptation of the newcomers than to inherent barriers within societal systems. It is not surprising then, that in many cities, it is “settlement agencies” or ethnocultural groups themselves that provide most or all of the interpretation services. However, many settlement services are only funded to provide services focusing on “settlement” for a limited time after arrival, and do not have the health expertise, the authority, or the financial resources to address health access needs. Unfortunately, in most cases, community-based interpretation services provided through immigrant-serving agencies have not been integrated with health services, and do not receive health funding. This marginalization has resulted in little sharing of expertise between settlement and health services, limited funding for service provision, training, or research, and limited impact on policy development. For immigrants, language access to health has remained a “settlement” and not a health issue, even though many immigrants require assistance communicating with their providers for many years, or even their whole life.

The Canada Health Act: Principles of Accessibility, Universality and Comprehensiveness

The health care system in Canada grew out of a commitment to removing financial barriers to health care. The Canada Health Act provides universal medical coverage to all its citizens. “The primary objective of Canadian health care policy is to protect, promote and restore the physical and mental well-being of residents of Canada, and to facilitate reasonable access to health services without financial or other barriers” (Canada Health Act, 1984). Three of the five key principles of the Canada Health Act (CHA) are of particular relevance in this context: access, universality, and comprehensiveness.

The Canada Health Act requires that provinces “provide for insured health services on uniform terms and conditions and on a basis that does not impede or preclude, either directly or indirectly, whether by user charges made to insured persons or otherwise, reasonable access to those services by insured persons”. This is the principle of accessibility. However, because access is not defined, it is not clear what would constitute reasonable access. Often, access is defined simply as the absence of explicit financial barriers (such as user fees). Universality requires that 100% of the residents of a province be entitled to insured services on uniform terms and conditions. Comprehensiveness requires that a health insurance plan cover all “insured health services provided by hospitals, medical practitioners and dentists, and where the law so permits, similar or additional services rendered by other health care practitioners.” All services that are “medically necessary for the purpose of maintaining health, preventing disease, or treating an injury, illness or disability” are included.

Health interpretation services have not to date been considered medically necessary. Instead they are seen as ancillary services that are not universally insured.

Rights to Language Services in Health Care

Claims involving rights of language access in health care in Canada are principally based on interpretations of the Canadian Charter of Rights and Freedoms, the Canadian Human Rights Act, provincial and territorial Human Rights Codes, the Canada Health Act, provincial health acts and the

Criminal Code of Canada. (For a more detailed discussion, please see the full original text of this paper.)

Canadian Research Related to Diversity and Health

How we understand the effects of language, culture, class, racism and poverty, both on utilization of health services, and on health status itself, is largely shaped by our assumptions as a society. These assumptions also determine what data is considered important to be collected, and what research areas are prioritized. This research, in turn, contributes to our beliefs about culture, ethnicity, class and poverty.

There are significant differences in research focus between the United States, the United Kingdom, and Canada. In the U.S., there has been an emphasis on the variables of race or ethnicity on health status and patterns of use, even though there have been varied understandings of what these variables represent (Krieger & Fee, 1994b; Goodman, 2000). In the U.K., there has been a greater emphasis on the importance of social class, which has shaped data collection and research differently (Krieger & Fee, 1994a).

In Canada, as a result of our unique history and culture, we have been most concerned about inequities in health and health access that are related to income, and to a lesser extent, to region (whether urban/rural or by province/territory). Research in Canada has focused on different patterns of utilization by "income status" rather than on differences related to language, culture or ethnicity. This is because Medicare in Canada was designed to address financial barriers to access. Data collection in Canada reflects these priorities. Canadian data on health status and service utilization does not usually designate ethnicity^d (Robinson, 1998; Sheth et al., 1997). Research in Canada has focused instead on strategies for assessing accessibility of services by income status. This emphasis is not accidental, but flows from our beliefs about ourselves as a nation, and our understanding of what affects health.

Canada has deliberately defined itself as a multicultural country, and has recognized and promoted awareness of differences between

cultures. There has been promotion of Canada as a cultural "mosaic", often without a critical analysis of sources of inequity. This has resulted in a body of research that focuses on beliefs and practices of specific ethnic groups, and almost never on "race". As in many countries, there has been confusion about the meaning of "race" in research. There has been a gradual evolution from defining race as a biological category, to understanding its importance as a social construct (Krieger & Fee, 1994a; Goodman, 2000), and increasing interest in researching the health effects of discrimination (Krieger, 1999, 2000).

Research has also been influenced by the approaches to cultural competence adopted by both the health system and the larger society. Where there is sometimes an emphasis on structural changes aimed at ensuring culturally competent care (e.g. bicultural providers, provision of interpreter services or development of culturally specific resources), other approaches have focused on providing "cultural sensitivity" training to providers. This approach often emphasizes culture-specific learning on the part of providers (often leading to stereotyping by ethnic group and ignoring socioeconomic, gender and other issues), rather than learning of skills that facilitate cross-cultural communication (Stevens, 1993b; Carrillo et al., 1999; Hamilton, 1996).

One unintended result of this research emphasis has been a tendency to attribute differences in health behaviours to underlying traditional beliefs held by various ethnic groups, while tending to ignore both the characteristics of "health culture" that may create structural barriers to equitable care, and the significant diversity found within a particular ethnocultural group.

"The use of culture as a way of accounting for whatever is seen as emotional, irrational, or illogical in the behaviour of the patient is commonplace in the literature on multiculturalism and health. The problem is that the focus becomes the patient and his or her cultural identity. Attention is diverted from other actors and other factors, and references to culture become simply another way of blaming the victim" (Kaufert, 1990).

^d An exception to this is coding related to First Nations (treaty status). Much information is available on both health status and health utilization of First Nations people (but not Aboriginal persons in general) because some data is coded as to Aboriginal status. Recent attention to the health status of Aboriginal peoples however, has raised the question about whether data should include some ethnic coding.

Summary

The international research on both the effects of language barriers, and strategies for addressing these barriers, cannot necessarily be generalized to the Canadian context. Any assessment of its applicability must acknowledge the historical, political and cultural context within which services are delivered and research is conducted.

Services for various constituencies that require language access services in Canada are uncoordinated and operated by a variety of community groups and institutions. Rights to language access also differ between these constituencies. The absence of legislation specifically requiring that health interpreters be provided in the health care setting has contributed to the failure of the health care system to take responsibility for provision of such services.

Some guarantees for access to health care in Canadian legislation, and more global rights provisions in the Canadian Charter of Rights and Freedoms, suggest that the rights to language access for speakers of non-official languages could be challenged. However, there are few provisions for enforcement of language access. In the United States, the federal government monitors and enforces rights of individuals to access public

institutions without discrimination on the basis of language (Perkins & Vera, 1998). In Canada however, federal support for enforcement has been limited. Despite legislation such as the Canada Health Act, there appears to be significant inter-provincial and territorial variation in access services for individuals who face communication barriers. The lack of enforcement capability may be one reason why there have been so few challenges brought forward. It may also be because the cultural context of language services in Canada may discourage rights challenges.

Until recently, lower courts in Canada have traditionally applied a cautious approach to guaranteeing minority language rights. However, the judgment in the Eldridge case provided a thoughtful analysis of access issues that have the potential for broader interpretation than the rights of deaf patients to communication with their health care providers. As the research discussed later in this report demonstrates, there is evidence that absence of language access services is also resulting in substandard health care to speakers of other minority languages.

Overview of Research Design Issues

Research questions related to language access may suggest either qualitative or quantitative methodology. Qualitative methods, such as interviews or focus groups, are used to address questions such as, "What types of problems do language barriers create?" or "How are these experienced by patients or providers?" They are often recommended where little is known about a subject. Quantitative methods are appropriate to testing theories or determining the prevalence of a topic of concern. They require a good understanding of the issues and are used to answer such questions as, "How many patients face language barriers?" or "How do those who face language barriers differ in use of specific services compared to those who don't?" These two methodologies are not mutually exclusive, and in most cases multi-method designs are recommended to describe problems and build and test theories.

Earlier descriptive research, such as case study-based research, graphically illustrated the risks of using untrained interpreters, and the effects on patients. With greater awareness, there has been more attention paid to measuring the effects, and other research designs have attained prominence. Administrative data is being used to compare utilization and health outcomes. Large population surveys are being analyzed to identify differences in health utilization or health status based on ethnicity or language ability. Most important has been the increase in the number of studies specifically designed to compare language groups on some outcomes (ranging from service utilization to differences in physician practice patterns), while controlling for a number of potentially confounding variables. Multivariate analysis has allowed for the exploration of the effect of language barriers while controlling for a number of other variables (e.g. age, severity of illness, insurance status, ethnicity, income, education) that may also affect the outcomes measured. This has enabled researchers to "disentangle" the multiple effects of ethnicity, language and economic status.

There are a number of research design principles that apply to any health research area. While it is beyond the scope of this review to provide a thorough overview of research principles, a

number of points with particular applicability to research on topics of language access should be highlighted.

Before initiating a research project, it is essential to undertake a review of the literature in related areas. This can not only alert the researcher to important findings which guide further research (and avoid duplicating work already completed), but it also provides important direction as to what type of research is best suited to the topic of study. It is necessary to be able to precisely frame the research questions and select an appropriate methodology. If quantitative methods are utilized, the outcome measures and any interventions must be defined, and valid and reliable measurements developed.

Any variables that may affect results must be clearly identified and controlled for. Within the area of language access and health care there are many potential intervening or confounding variables. These may include client demographic factors (socioeconomic status, gender, education or ethnicity), type or severity of disease, the client's regular source of care, and the practice style and experience of the provider. There is also often an assumption that the provision of language access service is the key or only intervention of interest, and this may lead to error. For example, studies indicate that simply being accompanied by another person can improve health outcomes (Kaufert et al., 1999). Another principle is that the subjects of research interventions must be similar, and that no bias should exist in who uses certain services and who does not. Selection bias (of institutions, providers, interpreters and patients) can easily occur and may affect results.

Research related to language access is governed by the same ethical principles as other forms of health research. All health researchers working with human subjects are required to abide by the guidelines of the Tri-Council Policy Statement (Medical Research Council of Canada, 1998), and obtain approval from specific ethics committees in the institutions with which they are affiliated. In addition, there is an increasing expectation that community consent for research will be obtained where feasible. This is an important requirement of working in First Nations

and Inuit communities (Kaufert and Kaufert, 1998). It may be more difficult to obtain such consent in ethnocultural communities that have multiple subgroups and no elected community representatives (Bowen, 1999).

For a detailed overview of general categories of research design, including descriptive research, survey methods, secondary analysis of data, experimental methods, and economic evaluation, please see the full original text of this paper. The text contains descriptions of the methodology, examples of studies utilizing this methodology, and discusses the potential of each methodology for further language access research. It also outlines many of the challenges faced by researchers in assessing the effects of language barriers, and provides an overview of the variables that should be considered. This includes a discussion of the issues involved in defining and measuring language barriers.

It has been noted that research related to language access is still in the early stages of development (Puebla Fortier & Shaw-Taylor, 1999). There are many challenges in design and

evaluation of research on issues related to language access to health care. Many of these challenges are related to the number, complexity and interaction of variables that must be considered in research design.

In Canada, the absence of both a coordinated system of health interpretation, and of any requirements that non-official language speakers be provided with professional interpreters, have likely contributed to the paucity of research. There are few researchers with experience in the area, and the isolation of language access issues from mainstream health research has resulted in little attention being paid to the issue. There are also particular methodological issues that present challenges to the use of certain research methods. Several methodologies show good potential for furthering research in this area. However, there are a number of limitations to use of these methods, related to the presence of language and cultural barriers and to the availability of data, that must be addressed.

Models of Interpretation Services

Health interpreters have only recently been recognized as professionals who have a critical role in the delivery of health care to patients who do not speak an official language (Jackson, 1998). With greater awareness of the risks of language barriers and inaccurate interpretation, there is increasing demand from providers and advocates for research related to models of interpretation services. As awareness of the need for skilled interpretation grows, so does the understanding that it is necessary to distinguish between various "types" of interpreters, and to identify problems that may arise through the use of interpreters. Research questions in this category include those related to: definition of the interpreter's role; models of service provision; effects of interpreters on communication; and standards of service provision (training, accreditation and evaluation).

The Interpreter's Role

What it means to be a "health care interpreter" (even when the discussion is limited to the role of "professional interpreters") is ill-defined. While the principal responsibility of an interpreter is to bridge the language barrier between individuals speaking different languages in order that they may communicate freely with each other (Downing, 1995), there is no consensus on the best way to achieve this. An interpreter may be viewed as a bilingual community worker, where interpretation is only one part of a larger role including advocacy or cultural mediation. At the other extreme are those who view health interpreters in the same category as court or conference interpreters – where they are expected to limit their role to accurate transmission of messages. This debate highlights the complexity of both the interpreter's role, and the challenge of "measuring" the input of interpreters in the provision of health services.

One result of the lack of consensus is often conflicting expectations of the interpreter's role (Kaufert & Koolage, 1984). However, little research has focused on the effect of interpretation on interpreters themselves, and their perspectives are often not included in planning or research. It appears that the view of interpreters as neutral "language processors" has often made their

experiences invisible. Interpreters often report their role to be stressful, frustrating and unsupported. (Esperon-Rayson et al., 1991; Loutan et al., 1999). In addition, interpreters often deal with painful and conflictive communication, which may (particularly in the case of trauma or abuse) affect them personally. This is a very real issue for interpreters from refugee communities, many of whom have had experiences similar to those of the patients for whom they are interpreting (Tribe, 1999; Loutan et al., 1999; Bowen, 1999). In other cases, interpreters are called on to provide emotional support, not only to clients, but also to providers. They may also feel personally responsible for failures in diagnosis and care (Stevens, 1993b).

It is essential for those planning and administering interpretation programs to have an understanding of the complexity of the task of interpretation, the roles expected by providers, clients and interpreters, and the way that assumptions within the "culture" of health care may prevent equity of care. It has been noted that often interpreters are called on for assistance – even when the patient speaks an official language – in order to help mediate the cultural expectations of both client and provider, and provide support to the patient (Hemlin & Mesa, 1996; Kaufert et al., 1998).

In spite of the lack of consensus on what the interpreter's role should be, it is generally accepted that effective interpretation must involve more than just interpreting "words". Interpretation must also be able to interpret meanings, and clarify misunderstandings that may arise due to differences between the cultures of the two participants in the health exchange (Dias & O'Neill, 1998). This recognizes that the culture of the patient includes more than his ethnicity. Individual values, beliefs, and previous experiences may or may not be similar to others in the client's ethnic community. There is also a need to explain and "translate" the culture of the medical system – the technical (and often exclusionary) language, the assumptions and practices, and the rights and expectations of patients (Jackson, 1998).

Models of Service Provision

Common approaches to providing interpreter services across Canada were listed in Section 2. Many rely on use of family and friends or ad-hoc untrained interpreters. In this section, we will focus on models of provision of trained or professional interpreter service. Much of the research related to the effects of language barriers and provision of interpreters has identified the risks of using family members or untrained interpreters. There has, however, been little research on the effectiveness of various models of professional service provision. The full text of this report outlines several models of professional interpreter services and the strengths and limitations of each.

Effects of Interpreters on Communication and Utilization

A number of studies have identified differences in utilization, satisfaction and compliance between patients with and without official language fluency. Fewer have attempted to directly compare patients for whom professional interpreters were available with those who did not have such access.

Few studies have compared different models of interpretation services. Kuo and Fagan (1999) implemented a survey of Spanish-speaking patients and medical residents about their experience and satisfaction with various methods of language interpretation (friend or family member, professional hospital interpreter, hospital employee who is not an interpreter, telephone interpreter, and physician who is proficient in the patient's first language). Levels of satisfaction with each method differed significantly between the two groups. While residents and patients had the highest level of satisfaction with professional interpreters, patients were more satisfied with using family members and friends, and less satisfied with telephone interpretation than were residents. The two groups also differed in the characteristics they felt to be important in an interpreter. Residents felt that availability and understanding of customs and beliefs were important, whereas patients felt that personal familiarity, gender concordance, and ability of the interpreter to assist them after the visit were more important (Stevens 1993b).

A Canadian study of clients, health professionals and interpreters working with the Inter-regional Interpreters Bank in Montreal, surveyed 288 health care workers regarding their expectations

of interpreters and satisfaction with the interpreters of the bank compared to volunteer interpreters (Mesa, 1997). Health care providers and clients expressed significant differences in satisfaction with professional vs. volunteer interpreters, preferring professional interpreters on measures of both interpreting skill and professionalism (e.g. maintaining confidentiality). This study found significantly larger differences in satisfaction with volunteer and professional interpreters than the study by Kuo and Fagan (1999) described above. However, a low response rate from participants and awareness that the study was an evaluation of satisfaction with a specific program may have introduced selection and response bias.

Interpreter Training

In Canada, training and accreditation for Sign Language interpretation has been more advanced than for other minority languages (Bird & McDonald, 1998). Processes for certifying translators, court interpreters and conference interpreters have also been more developed than for what is termed "community interpreting". There are a number of interpreter training programs in Canada; however, they vary from one-time pilot programs (Stevens, 1993) to established certificate and diploma courses. A 1997 survey identified seven interpreter training programs in Canada that prepare interpreters for health care settings (Roat and Okahara, 1998). All but one of the programs embedded health interpreter training into programs for general community interpreting. Almost all programs in Canada simultaneously train interpreters from a number of different languages. Exceptions to this are training programs for Inuktitut speakers in Nunavut and Nunavik. Both the Nunavut Arctic College (Penney & Sammons, 1995) and the Adult Education Department of the Kativik School Board (KSB) provide interpreter training programs for Inuit interpreters. The KSB program provides basic modules in the areas of Education, Social Services, Law and Medicine, and includes supplementary modules on a number of topics such as mental health (Raymond, 2001).

Training has been developed at regional and provincial levels, with significant differences found between provinces (Steyn, 1994). Ontario has adopted a model of "cultural interpretation", and some provinces have undertaken activities to develop provincial standards and services (Affiliation of Multicultural Societies and Services Association of British Columbia, 2000). In other

provinces there has been little attention to the development of standards, and health interpretation programs may only be available through specific agencies (Stevens, 1993b). Although training programs have been developed in many provinces and territories, there has been relatively little coordination and information sharing between programs (Dubieniski, 1998).

At a recent national symposium on language access to health care, the "Catch 22" of interpreter training and employment was identified (Rochefort, 2000). The absence of standards and policies requiring professional interpreters results in low demand (although not low need) for trained interpreters. Many interpreter training programs therefore do not have enough students to offer the courses regularly, as students are unlikely to pay for courses when employment is uncertain. A review of the Montreal Inter-regional Interpreters Bank found that the yearly salary of interpreters averaged \$1,587 (Mesa, 1997). A lack of trained interpreters contributes to a situation where there is continuing reliance on untrained interpretation. Participants recommended the development of a coordinated, national response to promote implementation of policies regarding health interpreter use, training and standards.

One initiative that has formed the basis for current work in setting and evaluating professional standards of practice for health interpreters, is the DACUM analysis. It was first commissioned by the Massachusetts Medical Interpreters Association (MMIA) and conducted by Dr. Maria Paz Avery for Educational Development Center Inc. (MMIA, 1996). The DACUM (Developing a Curriculum) is a method of occupational analysis for professional and technical professions. This process is also used in Canada for defining needed competencies for interpreters.

The DACUM has proved to be a useful development tool for a number of health roles, and the development of standards shows great promise in clarifying one of the variables of interpretation research (i.e., controlling for the variable of interpreter competence).

An additional challenge related to standard setting is the need for policy development and training for providers in working with interpreters. Even with skilled interpretation, optimum quality of communication cannot be achieved without provider awareness of the need for, and competence to work effectively with, interpreters. Providers from a number of health professions

have recognized this and developed specific guidelines for working with interpreters (Phelan & Parkman 1995; Smart & Smart, 1995; Massachusetts General Hospital Interpreters Office, 1998; Poss & Beaman, 2000).

Accreditation and Evaluation

Closely related to issues of training are those of accreditation. Accreditation generally involves a test of skill that is external to any course taken, and as such is a mechanism for ensuring equivalent standards across a variety of training programs. It is important that accreditation be coordinated at the national level, and that the process incorporate both the complexity and the scope of the interpreter's role. Evaluation refers to the ongoing assessment of skill and performance and is the responsibility of the employing agency. Little research has been done in this area.

Research Priorities

Many jurisdictions are requesting assistance in determining the most effective model of service provision. Research is needed in two areas. One relates to comparative evaluation of various forms of interpretation through assessment of patient and provider satisfaction, and by content analysis of interpretation accuracy. The second need is for economic evaluation of models for a particular setting. Institutions, cities and regions vary dramatically in the number of health encounters requiring interpretation services, and the number of languages in which these services are needed. A practical challenge then, is to design models that are both acceptable and cost-effective for a variety of situations. Developing appropriate models is a particular challenge in a country such as Canada, where there is a relatively small population spread over a large area. While the majority of non-official language speakers live in a few large Canadian cities, most smaller cities and towns also have smaller populations who face language barriers. In northern areas providers may be "minority language speakers", and the patient and most members of the community may communicate mainly in an Aboriginal language.

The potential of tele-medicine in addressing language access to health services has not been well explored. This technology, now used in Canada to address distance barriers, appears to be particularly useful where diagnosis is dependent on culture and language, such as in the practice of psychiatry. Video conferencing has

received high levels of acceptance from patients in a variety of settings. It may also be useful in certain well-defined situations, where a provider of the same background may be available in another city. This response however, does not rely on interpreters, as it is a strategy that increases the number of language-congruent encounters.

An area that shows promise and requires more research is that of creating roles for bilingual community health workers, who provide health interpretation as one of their functions (Stevens 1993, Jackson 1998).

Summary

As the following sections will illustrate, there is sufficient evidence on the negative effects of language barriers on health care access and quality of care, that attention should be directed to the practical issues of developing standards of

practice and appropriate models of service delivery for the Canadian environment.

While there is continuing debate about how the interpreter role should be defined, there is sufficient consensus on core competencies that these should form the basis for training programs. Although there are many models of interpretation services provision in Canada, both availability and quality of services vary widely. Some initiatives have been developed to address standards of practice, however there is a need for these to be expanded and coordinated at the national level. Training must prepare interpreters to perform a variety of roles and must also be required for providers who work with interpreters. Research is also needed to determine the most appropriate models of interpretation services for the distribution of the Canadian population.

Effects of Language Barriers on Patient Access and Care

Introduction

This section reviews current research on the impact of language barriers and language access programs, including: Estimating the need for language access programs; effects of language barriers on initial service access; effects of language barriers on quality of care; and effects of language barriers on health and utilization.

It is important to note that many of the studies discussed in the following sections have been conducted in other countries. Caution is therefore needed in generalizing study results to the Canadian context. Many studies on language access have been conducted in the United States, spurred in part by the interest of managed care organizations in addressing cost-effectiveness issues. Unlike Canada, the United States does not have universal health care insurance. Therefore, any investigation of access will be affected by the fact that many respondents face financial barriers to health care.

In addition, many studies on language access in the United States have focused on the Hispanic population, which is the largest minority language group in that country. This is a highly diverse population, comprised of both native-born Americans, and immigrants from a number of different countries (including significant numbers of "undocumented" immigrants who face additional barriers to access). Much of the published research has focused on immigrant languages. There has been less attention in North America to speakers of Aboriginal languages, or the Deaf community. This report reflects that emphasis. As acknowledged by the study authors, many of the studies have limitations – including sample size, possible biases in selection of participants, or failure to collect data on, and control for, potentially confounding variables (e.g. education or socio-economic status). There is also significant variation in how the presence of a language barrier is defined and measured. The presence and/or skill of the interpreter is often not noted. However, there are a number of

well-designed studies that provide consistent results.

Estimating the Need for Language Access Programs

The first step in developing appropriate models for addressing language barriers is to obtain an accurate assessment of need. This involves both a) estimating the numbers of individuals who require interpretation for health services, and b) estimating the proportion of those who require health interpretation services who actually receive them.

Need for Interpretation Services

It is estimated that 17% of Canadians have a mother tongue other than English or French. Approximately 10% of the population speaks a "non-official" language at home. On arrival in Canada 42% of immigrants speak neither French nor English (Marmen and Corbell, 1999). This proportion is higher for many refugee populations. One quarter of Aboriginal peoples report a mother tongue other than English or French (Statistics Canada, 1998). This increases to 90% in Nunavut, where 26% of Inuit are monolingual (Penney, 1994). According to the Canadian Association of the Deaf, there are 300,000 Deaf persons who rely on ASL for communication, out of a total of 1.2 million who are deaf or hard of hearing (Wood, 2001). French-speaking individuals living outside Quebec (approximately 3% of the Canadian population living outside of Quebec report French as the language used at home) and English speakers living in Quebec (10.5% of the Quebec population) may also face similar barriers (Bird and McDonald, 1998). There has been an increase in the number of residents who speak neither official language. The shift in source countries of immigration to Asia, Africa and Latin America contributes to greater linguistic diversity.

While we know that the number of Canadians who require an interpreter for health care is at least one in 50, the proportion of Canadian residents

who speak neither of the two official languages (Marmen and Corbell, 1999), the upper limit is much harder to determine. It may be as high as one in ten – the same proportion as Canadians who speak a non-official language at home. The percentage will differ significantly between cities and regions, and will be higher in cities where there are large numbers of immigrants, or in northern areas where Aboriginal peoples comprise a large percentage of the population.

The number of persons requiring language access services will also depend on the specific area of health services. For example, in a region where most Aboriginal young people speak English or French as their first language, access to maternal/child health services may not be hindered by language barriers, although there may still be significant cultural and systemic barriers to equitable care.

Current Research Approaches

There appears to be little research that has determined overall need for language access services. While many studies have been at the institutional level, these are often informal estimates and may not be published. Often, a survey of either providers or patients is utilized (McEntee, 1993; Andrea & Renner, 1995; Cross-Cultural Health Care Program, 1996; Drennan, 1996; Leman, 1997; Rader, 1998; Bischoff et al., 1999). Many institutional assessments are only disseminated internally or in the local area.

In Canada, perhaps the most common methods of estimating need at the community level are by needs assessments, focus groups, or consultations with community representatives. Such consultations consistently emphasize that immigrant and refugee communities, Deaf persons, and many Aboriginal peoples (particularly First Nations) consider interpretation for health encounters a priority (Stevens, 1993b; Stephenson, 1995; Canadian Nurses Association, 1995; Calgary Multicultural Health Care Initiative, 2000). However, it is important to note, particularly in the case of immigrant communities, that the proportion of the population that requires services can differ widely both between specific ethnocultural communities and over time. While there has been a steady need for interpreters for immigrant communities, the actual languages in greatest demand are often linked to current immigration trends (Cross Cultural Health Care Project, 1995).

Proportion of Those Facing Language Barriers Who Receive Service

Estimating the need for an interpreter is based on the experience of one or more of the participants in a health interaction. Estimating the proportion of those patients who require language access services who actually receive them is further complicated by the difficulty of defining what is meant by "interpreter". Only a few studies estimating need have attempted to differentiate between types of interpreters. Often, any form of interpreter is considered equivalent whether this is a family member, community volunteer, non-medical hospital staff person, or professional interpreter. Although some researchers note the kind of interpretation provided, others do not, and the type of interpreter used may not be a variable in the analysis. It is often found that interpreters are not called even when they are needed (Baker et al. 1996, Stevens 1993b, Ebert & Heckerling 1995; Hornberger et al., 1997;) or that there is reliance on ad hoc interpretation. For example, in a 1996 study, Baker et al found that interpreters were used in 26% of cases, but in an additional 22% of cases they were not used even though the patient felt they were needed. When both the patient's English and the provider's Spanish were poor, interpreters were still not called in 34% of cases. As well, 87% of patients who did not have an interpreter felt that one should have been used. This study also noted the type of interpreter used: nurse, 28%; physician, 22%; other people in the emergency room, 16%; professional interpreter, 12%; family members, 12%; hospital clerks, 11%.

Implications for Canadian Health Services

There has been little formal assessment in Canada of the prevalence of language barriers in health care encounters. Attempts to develop estimates are usually based on extrapolations from general population estimates, or of estimates developed by a specific institution. Population-based estimates include reviews of immigration landing statistics, reports from English/French as a Second Language programs or the public school system, local surveys, or consultation with community respondents. Several institutions have undertaken local assessments, and others are in the process of developing strategies for estimating need. Tracking the language preference of current patients, or collating requests for interpreters are two of the methods used.

In Canada, because neither ethnicity nor language are routinely coded in administrative

health data, it is not possible to undertake secondary analysis of this data to determine estimates. While census and household activity surveys collect data on language usage patterns, this data has not yet been used to develop preliminary estimates of unmet needs for health interpretation services. Immigration data may provide some useful information on the numbers of persons arriving in Canada by first language, and ability to speak English or French. However such figures prove less useful over time due to inter-provincial/territorial migration, uncertain rates of second language acquisition, and natural increases in the size of the community^e. Figures on numbers and first languages of ESL students may also provide one perspective, but will understate the needs of those who have been in Canada for a longer time and those who, for a number of reasons, may not be attending language classes.

The focus of research in this area should be on assisting health care providers and communities to develop models of service for addressing language access. In addition to obtaining an accurate assessment of numbers of language-disparate encounters, it is also necessary to determine the types of interpreters used in the encounters; reasons why interpretation was not provided; quality control methods for staff interpreters; qualifications of interpreters; training provided; evaluation; presence of language policies; data collection; and service coordination methods (Cross Cultural Health Care Project, 1995).

Canadian-based research is essential. The research approaches developed in other settings, however, can provide guidance to Canadian initiatives in this area.

Effects of Language Barriers on Initial Service Access

Language 'barriers' have been associated with both higher and lower rates of service utilization. Analysis of utilization patterns associated with language fluency indicate that some of the observed differences may be due to differential effects of: a) language barriers to initial access, and b) communication barriers affecting diagnosis and treatment (Bowen, 2000). The first barriers prevent a person from presenting for assessment and care, while the second affect the quality of

care obtained. The research indicates that there is a general pattern of lower use of many preventive and screening programs by those facing language barriers. Higher use has been reported for some emergency department services, and for additional tests ordered to compensate for inadequate communication.

It is important to note that utilization may be determined by either the patient or the provider. The patient most often initiates first contact with the health system. However, referral for specialist consultation, diagnostic testing, return visits or prescription of pharmaceuticals is determined by the provider. Even participation in preventive programs may be physician-initiated (rather than patient-initiated) through the course of a routine or other visit.

This section focuses on barriers to initial access to care.

Acculturation

Acculturation is a key concept related to research on utilization patterns. This is the process by which individuals entering a new society adopt more of its beliefs, values and practices and become similar to others in the host society. As individuals become acculturated to North American culture, for example, it is proposed that they are more likely to have health beliefs, practices and utilization patterns similar to those of the general population. In many studies, language has been assumed to be a measure of acculturation rather than the primary variable of interest; however, as the following research indicates, recent studies suggest that language proficiency itself may be the determining factor.

Access to Preventive Programs

Significant differences in utilization of preventive programs by official language proficiency have been found consistently in the research. This pattern is found for a range of conditions and is fairly consistent across countries. Most of the research has focused on screening programs such as mammography or cervical cancer screening, where good data is often available.

There are few North American studies that specifically examine the impact of language on utilization or preventive programs, but two other

^e While births to parents who do not speak an official language may not increase the number of persons who require interpretation, they will increase the number of interactions for which an interpreter is needed.

categories of research do provide useful perspectives: research that compares different ethnic groups where language emerges as a likely factor explaining differences, and research that compares different ethnic groups but does not measure or account for language fluency separate from "culture".

A number of studies focus on utilization of cancer screening programs (Fox & Stein, 1992; Naish et al., 1994; Solis et al., 1991; Marks et al., 1987) For example, Fox and Stein (1991) examined use of screening mammography by racial/ethnic groups in the United States, using a bilingual, random digit-dialed interview with more than 1,000 women. They found that the most important variable that predicted whether women of all racial groups had a mammogram was whether their doctors had discussed mammography with them. Hispanic women, compared to Black or white women, were less likely to have physicians who discussed screening with them.

Initial Access to Mental Health, Rehabilitation and Counselling Services

Access to mental health and counselling services is an area of particular concern relative to interpreter use. In addition to general barriers to first contact, there are additional concerns related to cultural differences in service provision, communicating concerns, beliefs about mental illness, and confidentiality. Even when patients have contact with the health care system, they may delay seeking care for mental health problems due to language barriers and underuse mental health services (Canadian Task Force on Mental Health Issues, 1988; Li et al., 1999; Mesa, 1997; Nyman, 1991; Trauer, 1995; Stuart et al., 1996; Roberts & Crockford, 1997). There are many barriers to domestic violence, sexual assault and addictions programs. Counselling program providers often make no accommodation for language access, instead referring clients to generic "helping" agencies such as immigrant settlement services. This results in a lower quality service for those who cannot communicate in an official language.

Other Differences in Initial Utilization

Studies have found language barriers to be associated with lower frequency of general check ups (Hu & Covell, 1986); fewer physician visits (Derose & Baker, 2000), and lower likelihood of having a regular source of care (Weinick & Krauss,

2000). Patients also report language to be a significant barrier to seeking care (Davanzo, 1992; Chak et al., 1984).

While administrators and researchers focus much attention on urgent or emergent needs for care, what may be less evident are the initial barriers to access in many other areas, including barriers to health promotion and education, HIV/AIDS education and counselling, participation in First Aid or CPR courses, access to emergency services, out of hours service, pharmacy service, and access to a range of mental health, counselling and rehabilitation services.

Canadian Research: The Effects of Language Barriers on Initial Access

Canada appears to lag behind the U.S. in research specifically related to language access, and research often includes a loose definition of "language" combined with ethnic and other factors. Many of these studies suggest that language is one factor affecting differences in utilization. More often however, these differences are attributed to differences in cultural beliefs and/or to lower socioeconomic status.

Canada's universal system of health care provides a number of advantages for health research. Unlike studies undertaken in the U.S., there is no need to control for insurance status. Universal health coverage also results in centralization of claims data for all residents by province or territory, and there are initiatives to improve consistency in reporting between provinces.

Canadian research indicates that Aboriginal women and some groups of immigrant women are less likely to have had mammography or cervical cancer screening (Hislop et al., 1996; Matuk, 1996a; Gentleman & Lee, 1997; Grunfeld, 1997; Sent et al., 1998; Maxwell et al., 2001).

Woloshin et al. (1997) analyzed self-reported utilization data on breast examination, mammography and Pap screening from the 1990 Ontario Health Survey. Of the study respondents in one city, 10% were non-English (6% French-speaking and 4% speaking other languages). He found that French speakers were significantly less likely to receive breast examinations or mammography. Women whose first language was neither English nor French were less likely to undergo Pap screening. These results persisted even when adjusted for social and economic factors, contact with the health care

system, and measures of culture. The authors noted that households where no English or French was spoken were excluded from the survey, resulting in an understatement of differences between official language and other language speakers.

It is recognized that in spite of universal entitlement, participation in prevention programs is linked to socioeconomic status. In addition, research has focused on cultural beliefs and practices that may function as barriers to participation and the concept of "acculturation".

Less research is available related to the effect of language barriers on access to health promotion and disease prevention information. Many of these initiatives occur outside the formal health system and are heavily dependent on language as they are "education" based. However, the research undertaken in this area provides evidence of significant barriers in the areas of health education.

A study of South Asian women regarding breast cancer detection practices (Choudrey et al., 1998), concluded that a lower percentage of the women surveyed practiced breast self examination than the general population. The authors noted that language and unfamiliarity with Western culture, rather than negative attitudes towards breast examination practices appear to act as barriers.

A study by Fitch et al., (1997) involved a survey of 513 older adults using the Cancer Knowledge Survey for Elders. The authors found that the proportion of non-English-language respondents with incorrect answers was higher than for English-language respondents on all items. The survey did not control for other demographic factors but it does provide information on ways in which language proficiency may, through affecting access to health information, result in delayed diagnosis of a serious disease.

A prospective longitudinal survey by Edwards (1994) explored the predictors of prenatal class attendance among immigrant women. Two variables were found to be significant predictors: self-rated English/French language ability and maternal age. Women who rated their official language ability as excellent or very good were more than seven times more likely to attend prenatal classes.

There have been other Canadian studies that suggest language may have a role in facilitating or

impeding access to health services. However, many of these studies used smaller samples and have not measured or controlled for language directly (Majumdar et al., 1995; Roberts & Crawford, 1997; Matuk, 1996b).

Most compelling are the consistent reports from health care users themselves, based on community consultations and direct assessment. Language barriers are consistently raised as one, if not the most important, of the barriers to care both in Canada and other countries (Stevens, 1993; Stephenson, 1995).

Implications for Canadian Providers: Research on Barriers to Access

There is good evidence that Canadians who do not speak an official language face important barriers to initial access to health care. However, because of universal health coverage, it is unlikely that these barriers have a significant effect on access for those who are acutely ill or injured. Canada provides a unique environment for assessing the relative importance of financial compared to other barriers to access, and it cannot be assumed that language barriers will have the same effect on access as in countries without universal health insurance. It is important that future studies investigate the effects of official language proficiency, while also controlling for factors related to ethnicity, immigration status, socioeconomic status and education.

Strategies for facilitating access must also recognize that barriers to access are not limited to physician and hospital care. Greater attention should be given to the barriers to prevention programs, particularly health promotion programs, which are aimed at providing health information and avoiding future health problems.

The Effect of Language Barriers on Quality of Care

The research referred to in this section includes work related to a number of different dimensions: the case study literature; differences in treatment of clients due to language barriers; health outcomes; patient satisfaction; patient understanding and "compliance"; and standards of ethical care.

Few studies were identified that focused specifically on language barriers as the major factor affecting care. However, a greater number of studies suggest that language may be an

important factor that results in different patterns of care experienced by various ethnic groups.

The Case Study Literature

Case studies are the most comprehensive source of information on the range of problems related to quality of care that may result from language barriers. While this literature will not be reviewed here, it should be noted that it is this body of research that first identified problems resulting from language barriers, and provided direction for future research. These reports not only illustrate, through concrete examples, the effects of language barriers on quality of care; but also present the context of service provision, and provide insight into the mechanisms through which care is impaired. Numerous examples of delayed diagnosis, misdiagnosis, inappropriate referral, failure to explain the patient's condition or recommended care, or failure to ensure confidentiality or obtain informed consent have been documented (Bowen & Kaufert, 2000a; Haffner, 1992; Holden & Serrano, 1992; Stevens, 1993b; Flores et al., 2000).

Differences in Treatment Due to Language Barriers

In the United States, increasing attention has been given to the question of inequities in health care provision and health status by ethnicity and race. A comprehensive review by Mayberry et al. (1999), supported by the Henry B. Kaiser Foundation, found that there were significant differences in quality of care and health status between ethnic/racial groups, that could not be explained by income, education, lifestyle, insurance status or other factors. This leads to the conclusion that there are inequities based on ethnicity within the U.S. health system. These findings cannot be assumed to apply to Canada, as provision of a universal, publicly-funded health care system addresses many sources of inequities, and the cultural and political climate is distinct. Although differences between ethnic groups in health status and patient-initiated utilization have received research attention in Canada, historically there has been little research directed towards determining whether there are any differences in treatment based on ethnicity. However, as there has been almost no Canadian research in this area, it cannot be assumed that inequities based on ethnicity do not exist. The focus of equity in Canadian research has been on differences in

health status and utilization according to socioeconomic indicators. However, one study found that members of ethnic groups in Quebec, while they showed similar rates of utilization of medical services, used more specialist and diagnostic services (Blais & Maiga, 1999). However, language was not controlled for in this study.

Less information is available on the specific effects of language barriers on treatment received. Research reviewed in the complete report suggests that language barriers may be associated with an increased probability of hospital admission (Lee et al., 1998); increased use of diagnostic testing (Hampers et al., 1999); less likelihood of a follow up appointment being given (Sarver & Baker, 2000); less likelihood of adequate pain control (Cleeland et al., 1997; Chan & Woodruff, 1999; Todd et al., 1993); and differences in prescribed medication (Brown et al., 1999; Gill et al., 1995). Particular risks are found in the areas of mental health, sexuality and reproductive health, addiction, family violence and rehabilitation/disability related services.

Specific Health Outcomes

Only a few studies have investigated differences in health outcomes related to language barriers. However, the literature suggests that there are many intermediate effects, such as delays in seeking care, misdiagnosis, inappropriate treatment, reduced comprehension and compliance, and malpractice injury that could affect health outcomes.

One of the most striking indications of the possible health outcomes of language barriers was described in a study by LeSon and Gershwin (1996) of young adults aged 20 to 34 with asthma. The purpose of the study was to determine the risk factors for intubation, intubation being a marker predicting death. Multivariate analysis was undertaken to determine the effects of variables such as socioeconomic status and other factors, while holding the effects of other variables constant. A number were found to be statistically significant: patients with language barriers (defined as an inability to speak English) were more than 17 times more likely to be intubated than patients with the same characteristics who were fluent in English. Other studies have explored the relationship of language barriers to reported drug complications (Ghandi et al., 2000); medical outcomes related to hypertension

and diabetes (Perez-Stable et al., 1997); and patient reported outcomes (Flores et al., 1998).

Patient Satisfaction

Patient satisfaction is the most recognized and widely used measure of effectiveness of provider-patient communication (Kaplan et al., 1989). It is also an outcome of care, and has been suggested as highly correlated with quality of care. One would expect that individuals who do not share a common language with their providers would be less satisfied with their care: most research on the topic confirms that this is indeed the case.

A number of studies have examined different aspects of patient satisfaction with care. These studies indicate that patients who do not speak an official language are generally less satisfied with their care (Carrasquillo et al., 1999; Baker, Hayes & Fortier, 1998; Morales et al., 1999; David & Rhee, 1998; Hu & Covell, 1986).

Patient Understanding and Compliance

Patient "compliance" is another issue that emerges from the literature as affected by language access. One would anticipate that patients who had more difficulty understanding their physician would be less likely to follow treatment directions. This appears to be the case. This is not only due to the obvious difficulties in obtaining accurate information, but also because good communication can be a source of motivation, reassurance and support, as well as an opportunity to clarify expectations (Kaplan et al., 1989).

A review of the literature reveals consistent and significant differences in understanding and compliance when a language barrier is present. Patients are more likely to report that medications were not explained (David & Rhee, 1998), are less likely to recall diagnoses and discharge instructions (Crane, 1997; and less likely to report understanding their diagnoses and treatment (Baker et al., 1996). They are also less likely to adequately self monitor blood glucose if diabetic (Karter et al., 2000) or maintain adequate blood levels of medication used to control asthma (Manson, 1988).

Evidence is not consistent on the effects of language barriers on appointment-keeping behaviour. Gruzd et al. (1986) conducted a multivariate analysis of 25 independent predictors

of "no-show" appointment behaviour. They found that language was one of six variables significantly associated with appointment keeping, while race/ethnicity was not. This confirms Manson's findings (1988). In a smaller study, Enguidanos and Rosen (1997) found no significant association between language and appointment keeping. However the small sample size, and lack of control for the type of patient condition and severity of symptoms may have affected results. Sarver & Baker (2000) also found that while there were differences in the number of follow-up appointments given by physicians based on language proficiency, there were no differences in compliance.

Ethical Standards of Care

There is also compelling evidence that quality of care for those who are not fluent in an official language is affected through failure of health care providers to meet ethical standards. Three ways that ethical care is compromised are through a) failure to provide care to the same standard as received by other patients, b) failure to protect patients' confidentiality, and c) failure to adequately ensure patients' informed consent to treatment.

Government reports have indicated that patients who do not speak an official language do not receive the same standard of care in Canada (Tang, 1999). While the most dramatic examples are those where misdiagnosis has resulted in injury or death, the research indicates that in spite of the best intentions of providers, patients who do not speak an official language are likely, on a day to day basis, to receive less protection in terms of ethical standards.

Obtaining informed consent is a critical standard in the delivery of ethical care, but open and frequent communication is essential for this to occur. When patient and provider do not share the same language, informed consent cannot be obtained. In addition, use of untrained interpreters risks patient confidentiality, another essential component of quality care. This is a particular concern in sensitive areas such as mental or reproductive health. Use of family members as interpreters also risks disrupting family relationships, or exposing children to psychological risk. (Haffner, 1992; Jacobs et al., 1995; Stevens, 1993b).

How Language Barriers Affect Health and Utilization

The research described above has identified differences in treatment, outcomes, satisfaction and "compliance" between patients who face linguistic barriers to care, and those who do not. But how exactly do language barriers result in these effects?

Analysis of Provider-Interpreter-Patient Interactions

One approach to investigating how the effects described above are accomplished involves presentation of narrative text showing the actual process of interpretation (Marcos, 1979; Ebden et al., 1988; Flores et al., 1999; Downing, 1992).

Marcos (1979) undertook a study of Chinese- and Spanish-speaking psychiatric patients and their providers. He attempted to identify the patterns of distortions associated with the interpreter-interviewer procedure with three different types of interpreters: psychiatric nurses with experience in clinical psychiatry; nurse's aides; and patient's relatives. While the author states that all were fluently bilingual, other qualifications were not identified. Content analysis of audio taped interviews were conducted by an English-speaking psychiatrist with the help of an interpreter. Marcos found three major types of distortions: a) distortions associated with the interpreter's language competence and translation skills, b) distortions associated with the interpreter's lack of psychiatric knowledge, and c) distortions associated with the interpreter's attitudes. He provided specific examples of each of the three types. An example of the type of distortion that can arise in the interpretation process is illustrated through the interpreter's transmission of a patient's response to the question about whether there was anything that bothered him:

Patient: "I know ... I know that God is with me. I'm not afraid, they cannot get me. [pause]. I'm wearing these new pants and I feel protected, I feel good, I don't get headaches anymore."

Interpreter: "He says that he is not afraid, he feels good, he doesn't have headaches any more." (p. 173)

The study concluded that clinicians evaluating non-English patients through an interpreter are confronted with consistent, clinically relevant,

interpreter-related distortions that may give rise to important misconceptions about the patient's mental status.

Downing, a professor and researcher in linguistics at the University of Minnesota, in his analysis of interpreted health encounters (1992) also demonstrated the risks in using untrained/volunteer interpreters. In one example, an encounter between a nurse practitioner, a patient, and the patient's son acting as an interpreter identified several kinds of miscommunication. In a conversation of only 25 exchanges, the following were identified:

- ◆ the interpreter failed to understand the provider's question and did not seek clarification (4 times);
- ◆ the interpreter interfered with the flow of the interview by asking for a paraphrase or explanation of particular words (4 times);
- ◆ the interpreter misinterpreted because of lack of understanding of particular words and idioms (5 times);
- ◆ the interpreter responded to a question himself without any attempt to interpret the question or his English response to the patient (6 times);
- ◆ the interpreter volunteered his own opinions or information regarding the patient (5 times);
- ◆ the interpreter's failure to interpret the question led the patient to try to guess what the question was and attempt an answer (4 times);
- ◆ the interpreter failed to interpret an answer offered by the patient (6 times);
- ◆ the interpreter seriously distorted the message in the process of interpreting it by adding information (2 times), omitting information (4 times), or changing the meaning (7 times);
- ◆ the reply that the practitioner received from the patient was the answer to a different question than the one she asked, but did not know it (2 times) .

These analyses demonstrate both the frequency of errors and the types of errors made in the interpretation process. They highlight the risks of using untrained, ad hoc interpreters or family members, and alert providers to the potential effects of mis-translation. Analyses can also

identify differences in communication where no interpreter is available.

Making the Links: Research on Patient-Provider Communication

A broader perspective on the potential impact of language barriers on health outcomes can be obtained by reviewing the research related to patient-provider communication. It is generally accepted that the provider-patient relationship is built through the effective use of language. Communication is central to the practice of medicine (Woloshin, 1995). Reviews of the literature (Kaplan et al., 1989; Stewart, 1995; Stewart et al., 1999, 2000) indicate that there is a relationship between the quality of patient-provider communication and the patient's health outcomes. In addition to the more obvious effects on satisfaction and adherence to treatment regimens, the quality of communication has been found to have a generally positive effect on actual patient health outcomes, such as pain, recovery from symptoms, anxiety, functional status, and physiologic measures of blood pressure and blood glucose levels. Kaplan et al. (1989) describe three basic communication processes associated with improved health outcomes: a) the amount of information exchanged, b) the patient's control of the dialogue, and c) rapport established. All of these processes are jeopardized in language discordant encounters (Betancourt et al., 1999). These processes can also be affected when an interpreter is used (Rivadeneira et al, 2000).

However, while the research suggests the ways in which language barriers may affect health outcomes, satisfaction and compliance, patients who lack proficiency in an official language are often excluded from research related to provider-patient communication, and the specific effects of language barriers on the provider-patient relationship have not been well explored.

Making the Links: Research Related to Health Literacy

Another source of insight into the possible impacts of language on health outcomes is the literature on health literacy. Recent research has highlighted the correlation between literacy and health status and health outcomes (Sarginson, 1997; Perrin, 1998). Low literacy has been linked

to lower health status, increased rates of hospitalization (Baker et al., 1997; Baker et al., 1998), and poor understanding of health conditions and diseases (Williams et al., 1998; 1998a). Patients with low health literacy are less likely to understand discharge instructions, and more frequently report medication errors due to inability to read prescription labels (Baker, 1999). Literacy is also a factor affecting ability to benefit from health promotion or disease prevention information (Sarginson, 1997). While low literacy is correlated with low education, low literacy is also found among well-educated persons who lack official language fluency.

Making the Links: Time Needed for Consultation

A recent time-motion study comparing physician time spent with non-English-speaking and English-speaking patients in an American hospital found that there were no significant differences in the time physicians spent providing care to the two groups. However, a significant number of physicians believed that they spent more time during a visit with non-English-speaking patients (Tocher & Larson, 1999). Studies such as this suggest another way in which quality of care is affected; additional time is required for communication when an interpreter is utilized. If all patients are given equal time for appointments, those who cannot communicate directly with the health provider are therefore less likely to achieve same quality of care. Inadequate time for communication may also result in reliance on laboratory testing to replace verbal evaluation.

Making the Links: Provider Continuity and Regular Source of Care

An issue of growing concern in many countries, including Canada, relates to the effects on health of not having a regular source of care (such as a family physician). Lack of a regular physician is associated with both lower health status and differences in utilization patterns and has been associated with the presence of language barriers (Weinick & Krauss, 2000). A recent Canadian study (Talbot et al., 2001) found that individuals who had been in Canada less than four years (a group most likely to experience language barriers) were twice as likely to have no regular doctor.

Ethnic Matching Between Client and Provider

It has been suggested that patients may have more confidence in care by providers from their own ethnic background (Health Canada, 1998; Saha et al., 2000). A number of studies have identified higher levels of utilization and satisfaction where there has been ethnic matching between patient and provider (Flaskerud, 1986; 1990; Ahmad et al., 1989; 1991; Snowden et al., 1995; Silgrove et al., 1997; Jerrell, 1998). Language congruence has been proposed as one explanation for this.

Summary

This section reviewed evidence of the impact of language barriers on quality of care from a number of perspectives:

- ◆ the treatment clients receive after presenting for care;
- ◆ the health of the client;
- ◆ patient understanding and compliance;
- ◆ patient satisfaction; and
- ◆ ethical standards of care.

In Canada, although there has been significant research on differences in treatment based on socioeconomic status (Dunlop et al., 2000) there has been almost no research on differences in treatment by ethnicity or language proficiency. While research from other countries suggests that there may be inequities in treatment based on ethnicity (Todd et al., 1993; Cleeland et al., 1997; Mayberry et al., 1999), similar research has not been undertaken in Canada. It is also unclear to what extent language barriers may account for observed differences in treatment between ethnic groups.

There is some suggestion that in Canada, those who lack official language proficiency may be more likely to receive specialist referrals or diagnostic testing (Blais & Maiga, 1999). This is consistent with some research in other countries that indicates that in some situations providers may "compensate" for language barriers by relying more heavily on laboratory or specialist assessment (Tocher & Larson, 1998; Karter et al., 2000). There is however, strong evidence that in Canada, as in other countries, those facing language barriers receive different services and quality of treatment in the areas of mental health and counselling (Canadian Task Force on Mental

Health Issues Affecting Immigrants and Refugees, 1988).

The question of whether treatment provided to patients is affected by language barriers requires significantly more research. In the absence of research focusing on questions of equitable treatment, it cannot be assumed that inequities do not exist. Until specific Canadian research is undertaken, findings of differences in treatment in other countries should be interpreted with caution. Research from one country often cannot be generalized to another because of differences in culture, history, and systems of health care provision.

There is also little direct evidence related to the effects of language barriers on health status. However, it is useful to make the links between the research on language barriers and the literature on provider-patient communication and health literacy; two closely related research areas. There is strong evidence from this body of research that poor provider-patient communication and lower literacy in the official language(s) is linked with poorer health outcomes. Effects on health outcomes due to differences in communication can be expected to be similar between countries.

There has been more research related to patient satisfaction. Language barriers are consistently associated with lower patient satisfaction with care. It is not clear to what extent findings from other countries related to patient satisfaction can be generalized to Canada, again because of differences between health systems. Many programs report that immigrants are often extremely positive about the health care system in Canada, and express high levels of satisfaction. Differences in satisfaction appear most closely correlated with social class, with those from less privileged backgrounds expressing the highest satisfaction (Bowen, 1999).

At the same time, most studies of immigrants in Canada, like those done in other countries, find that one of, if not the greatest, barrier to access reported by newcomers is that of lack of interpreters or bilingual providers (Stevens, 1993b; Stephenson, 1995; Calgary Multicultural Health Care Initiative, 2000). Canadian research also indicates that there is much higher satisfaction with professional compared to volunteer interpreters. A survey by the Montreal Inter-regional Interpreters Bank of 68 clients found that 76% of clients preferred dealing with a professional interpreter when consulting medical

personnel; 88% had more confidence in the accuracy of interpretation provided by professional interpreters, and 83% had more confidence in the discretion of a professional interpreter (Mesa, 1997). This indicates that even if many arrivals are appreciative of health services in general, their satisfaction with specific encounters may be low. Research on this topic, therefore, requires careful assessment of these two aspects of satisfaction.

Satisfaction with care by Aboriginal peoples is often low, however, there is greater evidence that there are differences in access and care related to geographical barriers, confusion over provincial/federal jurisdiction for Aboriginal health coverage, and distrust of health services based on historical and personal experience of discrimination (Canadian Nurses Association, 1995; Aboriginal Health and Wellness Centre, 1997; O'Neil et al., 1988; O'Neil et al., 1999). While language barriers are expected to increase dissatisfaction, the importance of language barriers in contributing to dissatisfaction is unclear.

The research indicates that language barriers have a negative effect on patients' understanding of their condition and the prescribed treatment, and therefore on patient "compliance". This is consistent with the general literature on provider-patient communication, that provides strong evidence that communication affects patient adherence (Stewart et al., 1999). There is no reason to suggest that findings related to compliance and communication would be significantly different in Canada than in other

countries. It may, however, be expected that adherence to treatment may be higher in Canada on some measures, as universal coverage removes many financial barriers to adherence to prescribed treatment.

There is solid evidence from Canadian programs that patients who do not speak an official language do not receive the same standard of ethical care as other Canadians. Case studies from across the country, found in both the published and grey literature, emphasize the failure of Canadian health services to ensure informed consent, and protect the confidentiality and privacy of patients who face language barriers.

In addition to research on provider-patient communication and health literacy, three other research areas are related to that of language access. Research related to ethnic matching of provider and client; research on the importance of a regular provider; and research related to time allocated to the patient-provider interaction may also provide useful insights on the importance of language barriers to health.

It cannot be assumed that the barriers to quality of care experienced by Deaf, immigrant or Aboriginal patients is equivalent. Most studies identified for this review have focused on immigrant communities. Research is needed to explore whether the effects of language barriers experienced by one language constituency can be generalized to others.

Other Effects of Language Barriers

Language barriers, and the absence of programs to address them, have other indirect but important effects. These include:

- ◆ Effects on health research and development of knowledge;
- ◆ Effects on health care providers; and
- ◆ Effects on costs of service provision.

It is recognized that both clinical and health services research tends to under-represent ethnic minorities, especially those who are not proficient in an official language (Hazuda, 1996; Ren & Amick, 1998; Larson, 1994). A study of original investigations on provider - patient communication found that only 22% of studies included non-English speaking persons, and that those who did so appeared to do so incidentally rather than systematically (Frayne et al, 1996).

Exclusion from research has both health and economic effects. The risk of certain diseases and conditions, and the response to specific drugs are only two of the areas where there may be ethnic/racial differences. Exclusion of certain ethnic groups from biomedical research may therefore mean that study results cannot be generalized to the entire population (Harrison, 1994; Cotton, 1990). Exclusion specific to language fluency may also prevent accurate assessment of the actual effectiveness of treatments (as opposed to efficacy) by not including the effects of language difficulties on treatment comprehension and compliance. In addition, members of language minority groups are prevented from benefiting from participation in cutting edge treatment for diseases such as cancer (Kaluzny et al., 1993; Roberson, 1994; Guilano et al., 2000).

Communication barriers also result in stress and lower job satisfaction for health care providers.

The presence of an interpreter poses difficulties in establishing the same quality of communication and rapport (Rivadeneira et al., 2000). Working with an interpreter can be frustrating. Providers may have less confidence that the work they are doing with patients is helpful, and express discomfort in seeing patients when there is a language barrier (Kline et al., 1980; Hoyt et al., 1981). Using an interpreter takes more time than direct communication, and often this is not time for which fee for service providers (e.g. physicians) are reimbursed. Language barriers may present challenges to learning for medical students and residents (Chalabian and Dunnington, 1997). Providers may also experience stress in attempting to meet ethical standards in providing health care, including the Codes of Ethics for their professions. Linguistic barriers to accurate diagnosis and informed consent may place a provider at greater risk of liability (Schneiderman, 1995). General studies about patient satisfaction or dissatisfaction related to patient-doctor communication indicate that complaints about doctors are usually due to communication problems and not technical competency issues (Rozovsky & Rozovsky, 1982; Stewart et al., 1999).

There is preliminary evidence that language barriers may have important effects on health care costs, through their impact on service utilization and health outcomes. However, the potential cost savings of skilled interpretation have never been adequately addressed. The full report reviews a number of studies that have attempted to assess the costs of language barriers, and the limitations of the research undertaken to date.

Conclusion and Recommendations

Effects of Language Barriers

There is compelling evidence that language barriers have an adverse effect on access to health services. Patients face significant barriers to health promotion/prevention programs. There is also evidence that they face significant barriers to first contact for care in a number of settings. Although limited research has been undertaken in Canada, research findings in this area are consistent with studies undertaken in other countries.

With the exception of access to mental health and counselling services, there is not at this point evidence that patients in Canada who face language barriers have reduced access to physician-initiated care. There is limited evidence that in some cases, Canadians who have lower official language proficiency may have higher utilization of specialist and diagnostic services. However, both initial access to, and quality of care provided for, psychosocial issues appears to be impaired by the presence of language barriers. More research is needed.

In many cases the rights to confidentiality and informed consent are not protected for patients who do not speak an official language, and they do not receive the same standards of ethical care as other patients. There is a paucity of research in Canada related to differences in treatment based on race/ethnicity. Based on the information currently available, there is some suggestion that in this country, for immigrants, language, rather than ethnicity, may be a more important factor in initial health care access, if not in health status. This is an area in which significant research is needed.

In addition to the direct effects on patient access and care, language barriers have a negative effect on provider effectiveness and satisfaction. Exclusion of non-official language speakers from clinical and health services research affects the generalizability of research findings and the development of knowledge.

There is evidence that providing language access services may result in benefits to a number of stakeholders:

- ◆ patients/clients (improved diagnosis, avoidance of unnecessary interventions, better health outcomes and satisfaction);
- ◆ providers (less frustration, less risk of malpractice);
- ◆ administrators (decreased liability and increased efficiency);
- ◆ health system (more appropriate use of services, and improved health outcomes); and,
- ◆ society in general (increased health and productivity of all citizens).

In spite of the risks of language barriers to access and quality of care, and the potential benefits of language access services to patients and providers, little responsibility for ensuring language access has been assumed by the health care system. It has been observed that while providers may intuitively or explicitly realize the risks of language barriers to patients and providers, they may find it inconvenient to address the issue of language access without externally articulated requirements and obligations (U.S. Office of Minority Health, 1999). While accessibility is a fundamental principle of Canada's health care system, to date access has been defined most often as the absence of explicit financial barriers to care. With the exception of interpretation services for Deaf patients, there are no specific requirements that professional interpreters be used.

While the designation of health as a provincial/territorial responsibility makes the development of a national response more difficult, there is a need for the development of national standards, and coordination of research and training. Strategies to increase language access must also be coordinated with other initiatives aimed at addressing the inequities in access to health services.

Current Challenges

Promoting Cultural Competence and Social Responsiveness

Provision of professional health interpreters is essential if equitable access to care is to be ensured. However, it is not a sufficient response. Provision of interpreters does not remove the obligation of health services to promote a range of initiatives to increase language and cultural diversity within the health professions. Relying solely on interpreters to provide a communication bridge to services that may be culturally uninformed or unresponsive, will not provide true access (Stevens, 1993a; James, 1998; Doyle & Visano, 1987).

Continuing effort is needed to increase the social responsiveness of health services, and the cultural competence of providers (Cappon & Watson, 1999). Too often, differences in communication and culture are viewed as problems belonging to minority communities, which health interpreters can help "overcome". Difficulties in access then are attributed to characteristics of communities, rather than to systemic barriers within the health care system. The assumption that failure to participate in prevention activities arises from "cultural beliefs", rather than structural barriers, is one example of this. The lack of health system response to the needs of clients for language access is an indication that there is continuing need for systemic change. Without addressing the larger issues of inequity, provision of language services will not have the desired effect. However, unless language access is obtained, this larger agenda will be hindered.

Greater effort is needed to develop roles that provide cultural interpretation and advocacy, and to develop specific health initiatives that respond to community needs (Stevens, 1993b; Vissandjee et al. 1998b). To ensure appropriate utilization of interpreters within institutions, policy requiring the use of interpreters is needed, along with provision for monitoring and evaluation. Training of service providers in working with interpreters is an essential component of cultural competence training, and should be a part of all health curricula. Interpreters must be viewed as members of the health care team, not simply as "language decoders". The relative "invisibility" of interpreters' needs and perspectives in the interpretation research highlights the marginal role to which they have been assigned to date.

It is also clear that not all barriers to language access can be best addressed by the provision of health interpreters. In particular, health promotion initiatives can probably best be provided through bilingual providers whether in a professional or paraprofessional role. Greater attention also needs to be given to the development of multilingual resources in a number of areas: health promotion, health service orientation, information on diseases and conditions, and patient care instructions. Development of a greater variety of quality plain language resources in English and French would also increase accessibility to health promotion and patient care information of many with limited official language fluency (Robinson & Miller, 1996; Gordon, 1996). This response would also improve communication for all clients.

Research Needs

Much of the research from other countries can be useful to Canadian policymakers and researchers. However, there are a number of areas where caution is needed in generalizing results. Different mechanisms may affect access to specialist or other more intensive care in a country with universal health coverage, compared to countries where there are significant disparities in insurance coverage. While a review of the U.S. literature related to ethnicity concludes that ethnic minorities receive less needed care (Mayberry et al., 1999), there is no evidence that these results can be generalized to Canada. Other factors related to the history, culture, organization of health services, and population density within a particular country may also affect results. While there is good evidence that the general findings on provider-patient communication, initial access to care, patient compliance and knowledge, and research participation may be similar between countries, additional Canadian-based research is required related to differences in treatment following assessment, and general satisfaction with the health care encounter.

An important limitation of much U.S. research is the focus on the Hispanic (Spanish-speaking) population. Sufficient research has not been undertaken on other, smaller language minority groups. Although there is no evidence that language barriers would be less for other language groups (and in many cases may be higher), the response to such barriers may differ between communities. Challenges related to validation of instruments for use with culturally diverse groups are of particular concern for

research which attempts to measure patient satisfaction or self-reported health status and health needs.

It is also essential to build on Canadian research that has highlighted the role of socioeconomic status in health status and patterns of utilization. Research in other countries often finds that non-English speakers are poorer than official language speakers. Canadian data suggests the same – persons with disabilities (including Deaf persons), new (though not established) immigrants, and Aboriginal peoples tend to be poorer than other Canadians. Recent research has emphasized the complex interaction between ethnicity, socioeconomic status and health. Socioeconomic status does not explain all differences in health between ethnic groups (Krieger, 1999; Mayberry et al., 1999). As indicated in this report, the research also suggests that official language proficiency is itself a determinant of health, and may interact with ethnicity and socioeconomic status. It is a variable that should be included in future research.

While in general immigrants do not identify any more unmet health needs than the general population, twice as many lower income immigrants report unmet health needs as compared to those with higher incomes (Chen, Ng & Wilkins, 1996). As lower income is linked to a decreased likelihood of fluency in one or more official language, more research is needed to determine whether language barriers to access, not simply income, might contribute to lower health status. Kinnon (1999) also notes that access is an area in which the distinction between recent and more settled immigrant populations is critical, and urged further research to explore the lack of access and need for appropriate services.

Models of Interpretation Services

While there are a number of interpretation programs operating in Canada, they vary in size, resources, model of service delivery and capacity to ensure quality. Additional research is needed to develop models appropriate for the distribution of Canada's population. Some of these models must be appropriate for regions with lower density, and high diversity, of non-official language speakers.

Strategies to increase language access to health services should not be limited to addressing access to physician and hospital appointments. Investment in the long-term health of the population must recognize that access to health

promotion and preventive programs is also important, and that strategies must meet the needs of clients and providers who work in a variety of professions and settings. Strategies should also be developed around the needs of clients, not of institutions.

Research has identified negative effects of language barriers not only on physician and hospital care, but also on long-term care, speech and occupational therapy, counselling and rehabilitation, community health nursing, pharmacy services, emergency and ambulance services, participation in CPR classes, access to out-of-hours services, abuse prevention and intervention services, home care, and health promotion and prevention (e.g. childbirth preparation, cancer awareness and prevention, HIV/AIDS education and counselling), and support for caregivers of the elderly and disabled. Therefore, a comprehensive strategy for addressing language barriers must take into account barriers to a variety of services, and match the form of service to the need. This may, for example, result in telephone interpretation for emergency services, in-person interpretation for a pre-booked appointment, use of bilingual providers for health promotion, and increased development of multilingual and plain language patient information materials.

Development of National Standards

A crucial issue is the development of standards for institutions, providers, and interpreters. These should include standards for interpreter training and for providers working with interpreters; the requirement for policy outlining situations where professional interpreters must be used; and development and coordination of accreditation processes for interpreters and institutions. A coordinated response to developing models of interpretation services appropriate for the distribution of the Canadian population is also needed.

Economic Evaluation

There are two forces currently promoting provision of health interpretation services in Canada. The first is based on patient rights and a commitment to ensuring quality of care for all patients. There is evidence that failure to address language barriers has an adverse effect on the health and satisfaction of patients and their rights to equitable standards of care. This, some argue, is sufficient

reason to provide language access services, and cost-benefit analysis should not be applied to issues of ethics and rights to care.

The second argument, that of cost-effectiveness, has been viewed in the past as a constraint to provision of language access programs. Programs, such as interpretation services, were understood simply to involve additional costs to the health care system, without significant economic benefits. As evidence related to costs and benefits has mounted however, there is a realization that provision of language access services may result in cost savings to both the health system and the larger society. The focus on reducing health care costs may therefore also serve as an impetus for developing strategies to address language barriers. In one U.S. hospital, a review of the effects of language barriers combined with requirements for cost reduction promoted creative restructuring which resulted in the reallocation of some existing positions to a new multilingual advocate model (Corso, 1997). In Canada too, there is increasing interest in undertaking cost-benefit analysis of language access programs.

Economic evaluation of health interpretation services raises two challenges. The first is that economic evaluation of health care is in its infancy. The methodology has not yet been adequately developed to accurately assess the "costs" of various health interventions. The other relates to the complexity of the task of defining and measuring both the inputs, and the outputs, of various interventions, including defining the "interpretation function" itself.

While it usually appears feasible to measure costs (inputs) of programs, (or absence of programs), measuring the effects ("benefits" or "outputs") is much more complex. There are a variety of possible outcomes, and many interventions may have delayed effects. There is often insufficient awareness of the potential costs to the patient and family, to the society in general or even to the larger health care system (community-based, continuing care, or preventive services, for example) over the long term. In addition, the data available through current collection systems does not provide the necessary information to provide cost estimates. Collaboration between researchers and providers of language access services is required.

It is however necessary that economic evaluation of interpretation programs be undertaken as one

component of a complete evaluation and planning process. Determining the effectiveness of the interventions, and analyzing ethical responsibilities are other necessary components of such an evaluation.

Recommendations

Based on this review of the literature the following recommendations are proposed by the author:

- ◆ Examine the feasibility of incorporating, as part of health system data collection, information on patient proficiency in official languages.
- ◆ Include, wherever possible, proficiency in an official language as a variable for analysis in health services research. This should always occur when ethnicity is one of the factors to be considered.
- ◆ Include in the review of health research proposals an assessment of whether those who are not fluent in an official language are eligible to participate, and promote inclusion of language minorities in both clinical and health services research.
- ◆ Develop strategies to increase health researcher awareness of the effects of exclusion of language minorities from health research, and methodological and ethical issues related to conducting health research with participants who have limited official language fluency.
- ◆ Develop initiatives to promote awareness of the importance of provider-patient communication, and the profession of interpretation within the health professions. Promote training on the effects of language barriers and working with interpreters as a required component of pre-service professional preparation.
- ◆ Develop strategies to promote dissemination of research on language access to policymakers and health service planners.
- ◆ Develop strategies to assist communities and institutions to develop models of service delivery appropriate for the variety of settings where interpretation is needed.
- ◆ Develop a coordinated national research strategy to further understanding of the impact of language barriers on health service utilization and health status of Canadians.

- ◆ Establish a centralized "clearinghouse" capacity for information and research on language barriers and language access programs in Canada.
- ◆ Develop a national strategy for health interpreter training, interpreter accreditation and standards of service provision.
 - Develop national standards of practice and appropriate models of service for the Canadian environment.
 - Coordinate strategies for training and accreditation of interpreters.
 - Include and coordinate strategies for official language, Aboriginal, visual, and immigrant languages.

Summary

Language barriers have been demonstrated to have adverse effects on access to health care, quality of care, rights of patients, patient and provider satisfaction, and most importantly, on patient health outcomes. In spite of universal health coverage, patients who lack proficiency in English or French may not have access to the same quality of care as other Canadians. There is also evidence that language barriers contribute to inefficiencies within the health system.

This document is intended to serve as the starting point for further dialogue among providers of language access programs, health administrators and policymakers, and researchers in Canada. It is hoped that it will promote further collaboration, program development and Canadian-based research related to language access to health care services.

Glossary

Aboriginal:

All indigenous persons of Canada who are of North American Indian, Inuit, or Metis ancestry, including those in the Indian Register. First Nations refers to those whose names appear on Indian Register maintained by the Department of Indian Affairs and Northern Development.

Back-translation:

A process by which original material is translated into a second language and subsequently translated back into the original language by a second translator. This method is used to monitor the accuracy of translation where the researcher cannot speak the two languages involved.

Deaf:

The word deaf, when the d is capitalized, as in Deaf, refers to those who belong to the cultural community of Deaf people. Many of these persons are pre-lingually deaf, and while they may learn to read and write English or French, learn these as second languages. In contrast, the words deaf, or deafened (with a lower case "d") refers to lack of hearing. Not all those who are deaf are members of the Deaf community or use sign language, the focus of our discussion here.

Immigrants:

"People who are, or have been at one time, landed immigrants to Canada" (Statistics Canada). A landed immigrant has been granted the right to live in Canada permanently by immigration authorities. Landed immigrants include both those who voluntarily immigrate to Canada, and refugees who are forced to flee their home countries.

Interpretation:

For the purpose of this report, interpretation refers to the process by which a spoken or signed message in one language is relayed, with the same meaning, in another language. Translation refers to the written conversion of one language into another. Two common forms of interpretation are simultaneous interpretation, and consecutive interpretation. In simultaneous interpretation the interpreted message is delivered nearly

instantaneously after the original. This is the common form of conference interpreting. Consecutive interpretation involves interpretation of segments of a conversation, with a lag between the original message and its interpreted form. Interpretation may also be categorized as proximate, meaning the interpreter is present in the encounter, or remote (e.g. by using telecommunication technology). American Sign Language (ASL) interpretation is most often proximate and simultaneous, while most other health interpretation is consecutive and proximate, although the development of communications technology has increased the availability of remote, and simultaneous interpretation.

Institutionally Complete Communities:

Those cultural communities that can provide a wide range of social, educational, economic and cultural services through providers of the same cultural background. In institutionally complete communities, individuals can obtain all or most services needed in their first language.

Multivariate Analysis:

A set of techniques used when the effects of several variables are to be studied at the same time.

Odds Ratio:

The ratio of two odds. Odds refers to the ratio of the probability of the occurrence of an event to that of the non-occurrence of the event.

Plain Language:

Language that is simple, clear, direct and uses common words. The intent of plain language is to make information accessible, especially to those who have low literacy skills, or low proficiency in a second language.

Self-rated Health:

How individuals describe their own physical and mental health.

Underservice:

The increased likelihood that individuals will, because of their membership in a certain population, experience difficulties in obtaining needed care; receive less, or a lower standard of care; experience differences in treatment by health personnel; receive treatment that does not adequately recognize their needs; or be less satisfied with health care services.

Validity:

The degree to which conclusions reached in a study are warranted.

Visible Minorities:

Persons other than Aboriginal peoples who are non-Caucasian in race or non-white in color. (Employment Equity Act, Canada).

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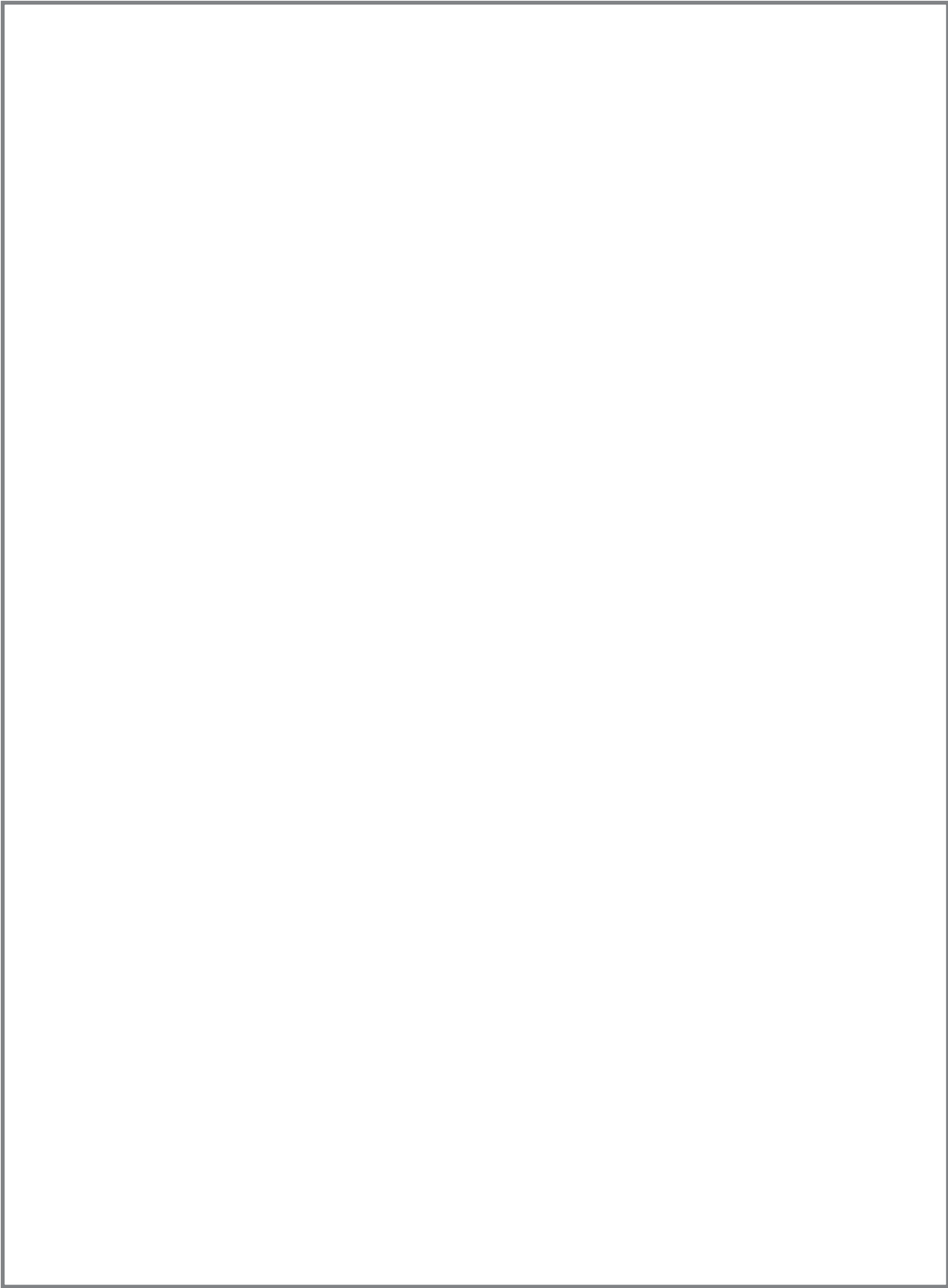
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Part III Barriers and Specific Population Groups

Document 1

Access to Care: Exploring the Health and Well-Being of Gay, Lesbian, Bisexual and Two-Spirit People in Canada

*Prepared by: Bill Ryan, Shari Brotman, Bill Rowe, McGill School of Social Work
May 2000*

Document 2

Report on the National Meeting of Canadian Researchers in the Field of Gay, Lesbian, Bisexual and Two-Spirit People's Health

*Prepared by: Bill Ryan and Shari Brotman, McGill School of Social Work, Montreal, Quebec
March 2001*

Document 3

Health Promotion and Population Outreach in the Black and Caribbean Canadian Community

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Access to Care:

**Exploring the Health and Well-Being of
Gay, Lesbian, Bisexual and Two-Spirit
People in Canada**

Executive Summary

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*With the Collaboration of
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Executive Summary

From mid-January until March 31, 2000, the McGill Centre for Applied Family Studies undertook an examination of health care access issues facing gay, lesbian, bisexual and Two-Spirit¹ (GLBT-S) people. An extensive review of scientific and community-based literature was conducted from the distinct perspectives of both women and men. This literature review documented the current knowledge base in GLBT-S health and health care² through an examination of research and community-based reports. The objectives of the literature review were to document gaps in the literature and identify areas needed in order to make the research literature, as it relates to GLBT-S people, more comprehensive³. Priority areas were related to:

- ◆ the health care and social service needs of gay, lesbian, bisexual and Two-Spirit communities (GLBT-S), and
- ◆ access issues in health care and social services related to being GLBT-S.

The second activity of the project was to conduct focus groups with GLBT-S people and their allies, related to access to health care and social services in different settings across Canada. Five focus groups were struck: two among Two-Spirit people— information about whom was direly lacking in the documentation— in an urban environment, which included the voices of urban and reserve-based Aboriginal people and their health care allies; one men's group and one women's group in a mid-size urban setting; and, one group for men and women in a rural setting. These focus groups enabled the researchers to validate the literature in the literature review, provide a Canadian perspective, and add the voices of Aboriginal and rural citizens.

The focus groups explored various topics related to people's perceptions of good health and good care, the barriers that exist to health and care, issues related to services, and how GLBT-S people use their resources to identify appropriate caregivers and quality care. The information collected reflects a wide range of experiences including those of people who are self-affirming, who have experienced difficulties in accessing care, and who (though citizens of Canada) feel

...When you're on a reserve you're native, but when you're off the reserve you're just like everybody else, and you lose that, and after a while that kind of wears on you. It's just like you lose that specialness of being in your community. And that's very strong. [f2 L 490-498]

Health, to me, means you have everything you need to live a full and energetic life...and that you feel supported...by the environment in which you live, and that's everything from the workplace to the home, to how you interface with general practitioners...more than just acceptance, that there's an awareness of... systemic barriers...just the idea that our needs and our place in the world is accepted and welcomed, and supported. [f3 L 251-269]

I had some patients... one of the women was in a motorcycle accident, and so her lover found out, ran to emergency and said, you know, 'I'm here to see so-and-so', and so the nurse said 'are you related?' and she said 'well we live together'... And the nurse said, 'well I'm sorry you can't see her'. So she was really upset, but she went, it was almost shift change and she sat in the waiting room and waited until the nurses changed and then went up, and a new nurse came, and she said 'I'm here to see so-and-so' 'are you related?' and she said 'oh yes, I'm her aunt'. 'Oh right this way please'. I mean, how humiliating. [f4 L 97-108]

I went to a community health centre once... I see the physician take his pen and write in block letters at the top of my file 'LESBIAN' and I was like, and I thought, I must be hallucinating here... So now anybody opening my file sees that... Now for somebody else who's coming, and maybe that's the first person they've told, and now all of a sudden it gets written in big block letters at the top of their files. I'm not telling anybody else this. And I'm not going back to that centre again, even if I'm dying. And it's the only place I could go for help'. So it's like these are the problems that are out there. [f1 L 956-965]

disenfranchised by the health care and social service system. Those participants who were Two-Spirit, rural-based, and belonging to ethno-“racial”⁴ communities felt even less well served than the majority of participants.

These discussions allowed us to document the coping and resistance strategies of dozens of men and women who felt strongly that both active and passive homophobia and heterosexism are still widely present in society generally and in their communities specifically, in the education of health and social service professionals, in the formulation of services and policies in health and social service establishments, and in the accreditation process and guidelines of Canada’s professional associations. Participants felt that their experience of being excluded and the lack of safety in their communities and in the health and social service system had a direct impact on their health (both mental and physical) and on their ability to access appropriate services. Participants generally felt that the health and social service system needs to be adapted to meet the needs of GLBT-S people and that health care providers must begin to address these issues in their practice through adapted knowledge, enhanced communication with their patients/clients and improved access to services. Participants expressed the need for developing partnerships between GLBT-S individuals, communities and the health care system in order to bring about these changes. In particular, participants stated that the onus was on more privileged or self-affirmed GLBT-S individuals themselves to advocate for the majority within the community who could not advocate on their own behalf. Thus affirming one’s self, being ‘out’ in other words, was seen as seminal in the ability to get good health care and achieve good physical and psychological health.

Recommendations touching on a broad range of issues (including adapting and expanding services, educating professionals and creating healthy spaces), were formulated so that the momentum gained during this research may be built upon and that the exclusion felt by the vast majority of GLBT-S people with regards to their health care and social services might be reduced.

I think access to...cultural spaces and cultural events where it's not only about the pain...So if I want to go to a group, it's not necessarily a group that's talking about trauma that I want to go to. There might be a time in my life and a place in my life for that, but... also for my own mental health, I do get isolated...You know, I have mental health needs, that are directly related to [my] Two-Spiritness... So I think there's a need for healthy community spaces, positive spaces. [f1 L 1571-1586]

And it took me 50 years to get here, so. I think, you know, that for 50 years I was an unhealthy person. At age 50, I literally transformed into a healthy person, 'why?' because I came out of this horrible, horrible closet, this room that... I was in was in a self-made prison. I wasn't very healthy. And so, for me, the positive affirmation of all of my self, my total self, is what I think is [just]... for me. [f3 L 225-231].

Well, each and every time you're visiting, say your GP, you could educate him or her... about some of the issues that you're facing, something about the issues that are coming up in the community. And what is the latest literature? What has he done? What has the medical association done to give him or her education? [f3 L 663-668]

I think that, you know, my friends who are white always have easier times in the medical system than my First Nation friends, who I go to the hospital with. One of them asked me to come with her, because I'm white. It's awful... And I think that each time you're more marginalized... that makes it harder and harder to navigate the system. And there are fewer and fewer doctors that are going to support you in your right to navigate that system. [f4 L 597-607]

Literature Review: At a Glance...

Counting Gay, Lesbian and Bisexual People: Methodological Barriers to Inclusion in Health Research

- ◆ Studies on gay and lesbian health rarely define homosexuality or lesbianism.
- ◆ It is impossible to validate various estimates of the percentage of gay men and lesbians among the general population, because of both the methods employed in research and the high risk of stigmatization experienced by this minority, which is an important inhibitor of their self-identification as gay or lesbian.
- ◆ The stigmatization experienced by gay men and lesbians seriously limits their ability to identify themselves as gays and lesbians to their health and social services professionals.
- ◆ The stigmatization experienced by gay men and lesbians also seriously limits the possibility of conducting research with large, reliable samples that are representative of their real diversity.
- ◆ The samples used in studies of gay and lesbian health are largely composed of white, middle-class, educated people with average or above-average incomes living in urban areas, frequenting gay bars and identifying themselves as gay or lesbian.
- ◆ Bisexual men and women are underrepresented in research samples, accounting for 10% or less of respondents. Furthermore, little relevant information appears to have been derived from studies on bisexual people due to poorly representative statistical samples.

Barriers to Health Care and Service Accessibility

Barriers associated with coming out to health care providers

- ◆ The coming out process appears to be a crucial stage in the life of gay men and lesbians.
- ◆ The heterosexism of health care providers and the person's discomfort with their own sexual orientation may be barriers to health care accessibility for gay, lesbian and bisexual people.
- ◆ Judging by the frequency with which negative attitudes are expressed by health care providers toward their patients' sexual orientation, the latter's discomfort and fears about coming out to a health care provider appear to be justified.
- ◆ Disclosure of sexual orientation is encouraged by the establishment of an atmosphere of trust and safety in the physician/client relationship.
- ◆ Non-disclosure of sexual orientation often engenders a feeling of alienation in the client.
- ◆ Disclosure of sexual orientation appears to be harder for gay men and lesbians from cultural communities and those with disabilities.
- ◆ It is important for health care providers to understand the process of discovering one's sexual orientation, so that they are better able to support people in their progress toward acceptance of their own homosexuality.
- ◆ Health care providers must not assume that all their patients are heterosexual and must be willing to accept the diversity of sexual orientations of their patients and clients.

- ◆ The relationship between gay or lesbian clients and their health care providers must be based upon trust, understanding and acceptance.
- ◆ It seems important for health care providers to understand the coming out process as well as to know what point the person has reached in that process and how they are coping with their sexual orientation.
- ◆ Gay men seem to be little inclined (or unfavourable) to consulting heterosexual health care providers.
- ◆ For men, coming out or disclosing one's sexual orientation to one's health care provider appears to result in greater satisfaction with the care received by the patient, but it also results in the health care provider devoting closer scrutiny to issues such as sexually transmitted diseases and AIDS.
- ◆ Gay men's discomfort with discussing their sexual practices may be an obstacle to their seeking medical attention.

Barriers linked to homophobia and heterosexism among health care providers

- ◆ Homophobia and heterosexism are barriers to health care and service accessibility for gay men and lesbians.
- ◆ The health care system appears to be pervaded by a heterosexist, and at times homophobic, medical discourse.
- ◆ Sexual orientation remains a source of discrimination, ostracism, opprobrium and stigma for gay and lesbian patients.
- ◆ The health care system appears to harbour entrenched prejudices and stereotypes about gay men and lesbians.
- ◆ Some health care providers seem to be more homophobic and heterosexist than others.
- ◆ The field of HIV and AIDS appears to be a prime means of access for health care providers to information about homosexuality.
- ◆ Homosexuality is still reflexively linked with AIDS-related issues and it appears to have accentuated homophobia in certain health care providers.
- ◆ Homophobia is present in the gay patient/health care provider relationship but

also in relations between health care providers.

- ◆ Psychiatrists appear to be the health care providers most unwilling to accept homosexuality as something other than a mental illness.
- ◆ Lesbians appear to develop protective strategies for coping with a health care system that is often hostile, sexist, homophobic, heterosexist and racist.

Barriers linked to the training of health care providers

- ◆ Health care providers do not appear to be trained to collect the information necessary to help gay men and lesbians.
- ◆ Health care providers apparently often confound sexual orientation and sexual behaviour.
- ◆ The quality of care received by gay men and lesbians appears to be affected by the health care provider's awareness or lack of awareness of the client's sexual orientation.
- ◆ Health care providers appear to be ill-prepared to deal with gay and lesbian patients.
- ◆ Gay and lesbian health care providers appear to have a better understanding of gay and lesbian health issues.
- ◆ Many health care providers have negative attitudes toward lesbianism, which undoubtedly affects the patient/professional relationship.
- ◆ Medical questionnaires and the questions asked by health care providers seem to be heterosexist, and focus primarily on contraception and heterosexual relations.
- ◆ The health care provider preferred by lesbians is generally a woman with a same-sex sexual orientation.
- ◆ Male health care providers appear to be the least supportive and least able to respond adequately to the needs of lesbians.
- ◆ Lesbians appear to be more at ease consulting a health care provider if they can be accompanied by their partner, a friend or a patient advocate.
- ◆ Lesbians are evidently turning to alternative medical approaches, stating that such health

care providers exhibit a better understanding of lesbian health issues.

- ◆ Some health care providers still believe that lesbians are a high-risk group for HIV transmission.
- ◆ Some lesbian health care providers apparently face discrimination, heterosexism and homophobia in their workplace, especially during their training.
- ◆ Health care providers receive little training about homosexuality as part of their educational curriculum and as a result, they often have little knowledge of the theoretical and psychosocial aspects of homosexuality.
- ◆ Psychiatrists appear to favour biogenetic theories to explain homosexuality.
- ◆ Health care providers appear to want more training about homosexuality.

Health Issues Faced by Gay, Lesbian and Bisexual People

Lesbian health

- ◆ In terms of gynecological problems, there do not appear to be any significant differences between lesbians and heterosexual women.
- ◆ Lesbians appear to suffer more frequently from vaginitis and irregular menstruation than heterosexual women.
- ◆ Many lesbians have had heterosexual relations in the past without the use of contraceptives or condoms.
- ◆ Screening for sexually transmitted diseases, breast cancer and cervical cancer appear to be often neglected by lesbians or their health care providers.
- ◆ Lesbians appear to be at lower risk of contracting HIV than heterosexual women.
- ◆ Lesbians appear to be more open to alternative medicine.

Substance abuse and addictions

- ◆ Studies which conclude that gay men and lesbians have higher rates of substance abuse and addictions must be read with caution because of problems in study design, sampling bias and inconsistent definition of terms.
- ◆ Substance abuse and addictions among gay men and lesbians may be linked to

homophobia, depression and the coming out process.

- ◆ Alcohol and drug abuse appear to be factors linked to domestic violence among gays and lesbians.
- ◆ Drug consumption appears to decline with age.
- ◆ Gay men and lesbians are not well served by mainstream drug and alcohol programs.

Mental health

- ◆ Gay men and lesbians appear to engage in certain high-risk behaviours such as smoking, alcohol and drug abuse and unsafe sex.
- ◆ Gay men and lesbians appear to be at greater risk for depression, suicidal ideation, confusion about their sexual orientation and hate crimes.
- ◆ These mental health problems are directly related to the stigma and shame associated with living in a homophobic society.

Domestic, sexual and homophobic violence

- ◆ Homophobic control appears to be a factor associated with domestic violence among gay men and lesbians.
- ◆ Homophobic violence appears to be a common phenomenon in the United States that has not received much scrutiny in Canada.
- ◆ Lesbians are apparently most frequently assaulted in their homes.

Gay and lesbian parenting

- ◆ Gay and lesbian families are invisible in US (and Canadian) national statistics.
- ◆ The most common means by which gay men and lesbians become parents are through previous heterosexual relationships.
- ◆ US and Canadian laws generally prevent or hinder adoption by gay and lesbian couples and individuals. Where laws are more open, attitudes of adoption workers often result in gay men and lesbians being discouraged from adoption.
- ◆ Many lesbians want to have children and artificial insemination appears to be the most frequently employed method.

- ◆ Discrimination apparently occurs in prenatal classes, medical follow-up care, fertility clinics, interactions with heterosexual couples, the gay and lesbian community, the family, society at large and so forth.
- ◆ Lesbians appear to be more satisfied with the services of midwives than physicians.
- ◆ Gay men wishing to become biological fathers face unique barriers and often create alternative arrangements such as co-parenting.

Lack of Information on Health Problems Other than HIV/AIDS in the Gay Community

- ◆ Various diseases seem to affect gay men more often than heterosexual men, especially certain sexually transmitted diseases and HIV/AIDS.
- ◆ Research on gay male health appears to focus primarily on the problem of HIV/AIDS.
- ◆ Research grants seem to be earmarked for gay sexual health issues, leaving aside other aspects of gay life.
- ◆ Gay sexual health appears to dominate the gay health research agenda.
- ◆ The most commonly reported social and health problems in gay men appear to be associated with the coming out and “pre-coming out” stages of self-acceptance.
- ◆ There are few studies on the incidence and prevalence of social and health problems among gay men.
- ◆ Knowledge of gay health issues after coming out appears to be limited to the aging process.
- ◆ The social and health problems of gay men appear to be strongly related to the coming out process, the lifestyles adopted by gay men or to sexual behaviour.
- ◆ There is a glaring absence of comparative studies on gay and heterosexual male health.

HIV/AIDS transmission among lesbians

- ◆ Lesbians are still often considered to be at high risk for contracting HIV due to their association with gay men, but this belief is not borne out by epidemiological studies.

- ◆ HIV-positive lesbians were almost always infected either by unprotected sexual relations with men or by exchanges of contaminated needles.
- ◆ Woman-to-woman HIV transmission appears to be unlikely and only four cases have been reported in the US.

Neglected Populations in Scientific Publications

Rural dwellers: what we know

- ◆ Gay men and lesbians living in rural areas tend to be invisible and are facing a hostile, homophobic environment that inhibits the development of their identity.
- ◆ Remaining unknown and invisible in rural areas appears to be a survival tactic for gay men and lesbians, or a means of coping with non-acceptance, discrimination, oppression, and at times, physical and psychological violence.
- ◆ Gay men and lesbians living in rural areas suffer from social and geographical isolation.
- ◆ In rural areas, the concept of a gay community is non-existent, whereas the concept of community ties is very pervasive.

Elderly people: what we know

- ◆ Demographic studies on elderly people do not distinguish between gay men, lesbians and bisexuals.
- ◆ Elderly gay men and lesbians seem to be invisible not only in society and the media but also in the gay community.
- ◆ Rural and urban environments do not offer the necessary support networks, and this may affect the lives of elderly gay men and lesbians.
- ◆ Elderly gay men and lesbians appear to be in a better position than their heterosexual peers in regard to the stigma of aging since they have already lived through the stigma associated with their sexual orientation.
- ◆ Little relevant information is available on the behaviour of elderly lesbians.
- ◆ Elderly lesbians do not appear to identify themselves in the same terms as younger lesbians.

- ◆ Elderly lesbians appear to receive little support from the lesbian community.
- ◆ Out elderly lesbians experience aging differently from their closeted peers.
- ◆ Menopause appears to be infrequently addressed in studies on lesbians.
- ◆ Elderly lesbians appear to be struggling against various myths and stereotypes.
- ◆ The cohort of gay men aged 40 to 50 today is perhaps smaller than past or future cohorts due to the AIDS epidemic.
- ◆ Elderly gay men and lesbians appear to be struggling against ageism and rejection on the part of younger gay men and lesbians.
- ◆ Contact with the gay community appears to favour the psychosocial adaptation of elderly gay men and lesbians to the aging process.

Youth: what we know

- ◆ It appears that the term “gay and lesbian youth” may apply to different age groups and may be used to refer to people aged 14–30.
- ◆ Gay men and lesbians under 30 and gay and lesbian adolescents do not appear to be target clienteles of research on gays and lesbians.
- ◆ Young gays and lesbians appear to be invisible and ignored by society, the public health system and research.
- ◆ The social and health problems of young gay men and lesbians appear to be intrinsically related to the coming out process and their acceptance of their own sexual orientation.
- ◆ Young gay men and lesbians appear to have more emotional, social and physical health problems than their heterosexual peers because of homophobia, heterosexism and the coming out process.
- ◆ Compared to older people, young gay men and lesbians have more difficulty negotiating the isolation and stigma associated with a homosexual identity.
- ◆ Suicide is a significant issue in the lives of young gay men and lesbians going through the coming out process.
- ◆ School does not appear to offer a safe environment for young gay men and lesbians.

- ◆ The primary and predominant sources of information on homosexuality for young gay men and lesbians are television and hearsay.
- ◆ Young gay men and lesbians appear to attach special importance to the confidentiality of the information they confide to their health care providers.
- ◆ Health care providers do not habitually inform young people of their right to confidentiality, which appears to inhibit young gay men and lesbians from disclosing their sexual orientation.
- ◆ Barriers to health care accessibility reported by gay men and lesbians include inappropriate language used by health care providers, absence or presence of questions on socio-sexual history, absence of educational and preventive literature directed at young gays and lesbians in health care establishments, the responses of health care providers, the failure to respect confidentiality, the ignorance of homosexuality among adolescents and the presence of heterosexism.
- ◆ Young gay men and lesbians apparently prefer to consult a health care provider with the same sexual orientation (apparently also preferring health care providers of age, gender and ethnicity that correspond to their realities).

People from Ethno-“racial” Communities: What We Know

- ◆ Knowledge of gay men and lesbians from ethno-“racial” communities is very limited.
- ◆ Gay men and lesbians from ethno-“racial” communities appear to be struggling against heterosexism, homophobia and racism.
- ◆ Gay men and lesbians from ethno-“racial” communities suffer from isolation due to rejection by their communities of origin but also by the gay and lesbian community.
- ◆ Gay men and lesbians from ethno-“racial” communities are underrepresented in samples.
- ◆ Studies of gay men and lesbians from ethno-“racial” communities are mainly US-based and not very representative of Canadian realities.
- ◆ Gay men and lesbians from ethno-“racial” communities are also coping with the

coming out process, but in a context of acculturation and racism.

- ◆ There is little or no knowledge of health issues affecting gay men and lesbians from ethno-“racial” communities, and little or no information is available on their interactions with the health care and services system.

Aboriginal people: what we know

- ◆ Little research has been done on gay men and lesbians from Aboriginal communities.
- ◆ Information on Aboriginal gay men and lesbians derives mainly from oral tradition, newspaper and magazine articles, poems, essays and novels.
- ◆ It appears that the majority of Aboriginal languages have a term to designate individuals considered to be neither men nor women.
- ◆ The terms “Two-Spirit” or “Two-Spirit people” appear to be more acceptable to many Aboriginals than the terms “berdache,” “amazon” or “gay/lesbian/bisexual.”
- ◆ Colonization and Christianity appear to be responsible for the exclusion of Two-Spirit people from certain Aboriginal communities.
- ◆ Aboriginal gay men and lesbians appear to be struggling against discrimination, homophobia, stigmatization and rejection by their own communities but also by the gay and lesbian community.
- ◆ As gay men or lesbians, it appears to be difficult to live on one’s reserve, but life in urban areas presents its own difficulties.
- ◆ There are few or no services and resources available for Aboriginal gay men and lesbians living in urban areas or on reserves.

Recommendations

The following set of recommendations emerge from the cataloguing of gaps and dilemmas that exist within the international and Canadian research on gay, lesbian, bisexual and Two-Spirit health care access as well as from the documented experiences of gay, lesbian, bisexual and Two-Spirit people and their allies who participated in the focus group discussions. Each of these recommendations is predicated upon the need for collaboration between health care providers, policy makers and GLBT-S communities.

1. Concerning the Education and Training of Health and Social Service Providers

The historic role that the health and allied health professions (most notably medicine, nursing, psychiatry, psychology, sexology and social work) have played in the pathologization as deviants of gay, lesbian, bisexual and Two-Spirit people places a special onus on these professions, and their educators, to right these wrongs.

- That professional schools across Canada recognize that lack of training on issues related to GLBT-S health has further marginalized GLBT-S people and led to them being in situations of greater health risk.
- That this lack of training on GLBT-S health and well-being issues be redressed through course content, research and consultation with these communities.

2. Concerning the Continuing Education of Health and Social Services Providers

Those professionals already in the field have received biased views of gay, lesbian, bisexual and Two-Spirit people, or were trained when the discourse of pathologization had been replaced by total silence.

- That a program similar to that of the Ministry of Health and Social Services of Québec be established, provincially and nationally, which has as its goals the correction of prejudicial attitudes towards GLBT-S persons, and the adapting of services to the needs of gay, lesbian, bisexual and Two-Spirit citizens.

- That professional associations across Canada be sensitized to the alienation felt by GLBT-S people with regards to their health care system and providers, with the view that these associations implement policies and training programs to sensitize their members.
- That health care organizations representing Aboriginal communities and professionals be sensitized to the needs of Two-Spirit people within their communities and in urban areas.

3. Concerning Adapting Services to the Needs of Gay, Lesbian, Bisexual and Two-Spirit People

Gay, lesbian, bisexual and Two-Spirit people have all the health and well-being concerns of any citizen of Canada. However, they have the added challenge of facing current and historic mistreatment by the health care system. This has led to the mistrust of health care and social services by gay, lesbian, bisexual and Two-Spirit people.

- That public sector health and social service institutions must begin to evaluate their “state of readiness” to provide gay-positive health care services to diverse GLBT-S individuals and communities. Initiatives must be put in place which address systemic, institutional and individual barriers to appropriate and sensitive care.
- That specialized services that respond to the unique health and social service needs of GLBT-S people must be developed and supported as allies to the public health care system. These services could include, but are not limited to: support to youth who are in the process of coming out, support to parents of GLBT-S youth, support to GLBT-S persons who are parents, services that offer education and training to sensitize the broader community (schools, professional schools, health care providers, etc), community mental health services, seniors

organizations, suicide prevention programs, etc.

- That health and social service organizations need to be sensitized to the fact that GLBT-S people have varying levels of unease when accessing services. There is a presumption by many, based on experience, that they must hide, or camouflage their sexual orientation in their interactions with health care and social service institutions and providers in order to receive adequate and equitable care. Organizational policies and services that take this fact into account and explicitly reach out to these populations do much to allay fears and build trust.

4. Concerning Policy Development

The absence of federal and provincial policy directives on gay, lesbian, bisexual and Two-Spirit people's health has contributed to access barriers and impeded the development of gay-positive health care services.

- That the federal government play a key leadership role in the articulation of best-practice with regards to the health and well-being of GLBT-S people. This includes bringing recommendations for adapting services to provincial health ministers as well as assisting institutions and providers through the development of training programs, guides and other materials on GLBT-S health and health care which can be applied across jurisdictions.
- That the federal government support research initiatives and demonstration projects addressing health care access and service delivery for GLBT-S people.

5. Concerning Research

Historically, research has been used to confirm prejudice, seek out the causes, and test treatments for «deviance». Recently, it has been limited to gay and bisexual men in the context of better understanding the vectors of the HIV pandemic. There is little, if any, research on the lives of gay, lesbian, bisexual and Two-Spirit people, the impact of stigmatization, the adapting of services, the impact of homophobia in health care, or how gay, lesbian, bisexual and Two-Spirit people live in Canada. This is particularly so in the

case of lesbian and bisexual women and again in the case of Two-Spirit people.

Research in the Field of GLBT-S Health and Well-being

- That research funders be encouraged to explore the health and well-being of GLBT-S people and the question of access to care.
- That research be conducted on the relationship that GLBT-S people have with their health and social service providers and health and social service organizations.
- That research be conducted in partnership with GLBT-S people through all stages of the research endeavour.

Research in the Field of Lesbian and Bisexual Women's Health and Well-being

- That research be encouraged and funded to study the situation of lesbian and bisexual women in Canada – a population that has been widely ignored and is seriously lacking in the kinds of contacts that gay men have established with health care providers in the last two decades.
- That research be undertaken respecting the differences between gay and bisexual men and lesbian and bisexual women, their understanding of health, their relationship with care providers, and their development of networks.
- That research be undertaken to better document the experiences of lesbian and bisexual women from ethno-“racial” communities in relation to health and health care access.
- That research include the experiences and needs of bisexual women.

Research in the Field of Two-Spirit Health and Well-being

- That research be undertaken to better document the lives and stories of Two-Spirit people, their relationship to their communities and to health and well-being.
- That Two-Spirit people be included explicitly in any policy formulation, research frameworks, outreach documentation or educational programs developed to increase access to care for gay, lesbian and bisexual people.

- That research include an analysis of the historic and current impact of colonialization on Aboriginal communities.

Research in the Field of Gay and Bisexual Men's Health and Well-being

- That research into gay men's health issues not be limited to epidemiology and the explicit vectors of HIV infection, but include interest in the lived experiences of gay and bisexual men, the impact of homophobia and heterosexism in their lives, their relationships with their communities, and their health care in general.
- That research be undertaken to better document the experiences of gay and bisexual men from ethno-“racial” communities in relation to health and health care access.
- That research include the needs and document the experiences of bisexual men.

6. Concerning the Place of Transgendered and Transsexual People

A recurrent theme in this study was the official absence of discourse concerning transgendered and transsexual people. Participants in the focus groups expressed consternation that the process was not inclusive of transgendered and transsexual people, and the literature review underlined the absence of data concerning their lives and their relationship with the broader gay and lesbian communities.

- That, as a follow-up to this study, a focus group be conducted to document the question of access to care for transgendered and transsexual people in Canada.
- That research be encouraged to look beyond the surgical and psychiatric aspects of transgenderism and transsexuality to see the persons who are transgender and transsexual, their lives, their experiences, and their relationship to health care in general, including mental health services.
- That, following discussions with this community, and with their consent, a collective decision be made as to whether subsequent initiatives be undertaken as

gay, lesbian, bisexual, Two-Spirit, transgendered and transsexual inclusive.

7. Concerning Building Upon the Current Project: Developing A Phase II Initiative

That a second phase of this project be initiated to:

- Further explore the experiences of gay, lesbian, bisexual and Two-Spirit people (or GLBT-S and transgendered/transsexual people) across Canada by constituting focus groups in several additional Canadian locations.
- Expand the research to include the experiences of those who are not represented in the current project or who are under represented, such as: gay, lesbian, bisexual and Two-Spirit people who are not fully self-affirmed and those living in isolated and remote communities, through a directed research program developed on the web with the support of gay and lesbian media.
- Duplicate the outreach undertaken with Two-Spirit people in Phase I with ethno-“racial” GLBT-S people by accessing key individuals who can facilitate the process of building trust with individuals in order to constitute focus groups in several communities.
- Establish a Best-Practices Guide on GLBT-S health and well-being for use by service providers, institutions and professional associations across Canada which would include an evaluation of their «state of readiness» to provide gay-positive services.
- Develop a training program, similar to that in use in Quebec, to be made available to other provinces.
- Create and test a model university level course on «Good Health and Good Care in Gay, Lesbian, Bisexual and Two-Spirit Communities» that will be made available to learning institutions across the country.
- That these initiatives be undertaken in conjunction with the establishment of a National Working Group on Gay, Lesbian, Bisexual and Two-Spirit Health and Well-being.

End Notes

- 1 The term Two-Spirit refers to Aboriginal people who are attracted, emotionally and physically, to persons of their own sex, or to persons of both sexes. The term also refers to Aboriginal people who are transgendered. Two-Spirit is an ancient term being reclaimed by individuals and communities that invokes a time, before European contact, when many Aboriginal communities held Two-Spirit people in high esteem.
- 2 The current project defines health from a broad perspective that incorporates the physical, psychological, emotional, social and spiritual components that contribute to health and well-being.
- 3 Given the paucity of published information available on bisexual and Two-Spirit people's health, the literature review focuses predominantly on gay and lesbian health and health care.
- 4 The term "race"/"racial" is purposefully set off in quotation marks in order to emphasize the fact that it is a socially, rather than a biologically, constructed concept or category associated with colonialism/oppression in which skin colour and other visible, socially selected traits are used to classify groups hierarchically.

NOTE: The original document is accompanied by an extensive bibliography. For the complete document, contact:

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Report on the National Meeting of Canadian Researchers in the Field of Gay, Lesbian, Bisexual and Two-Spirit People's Health

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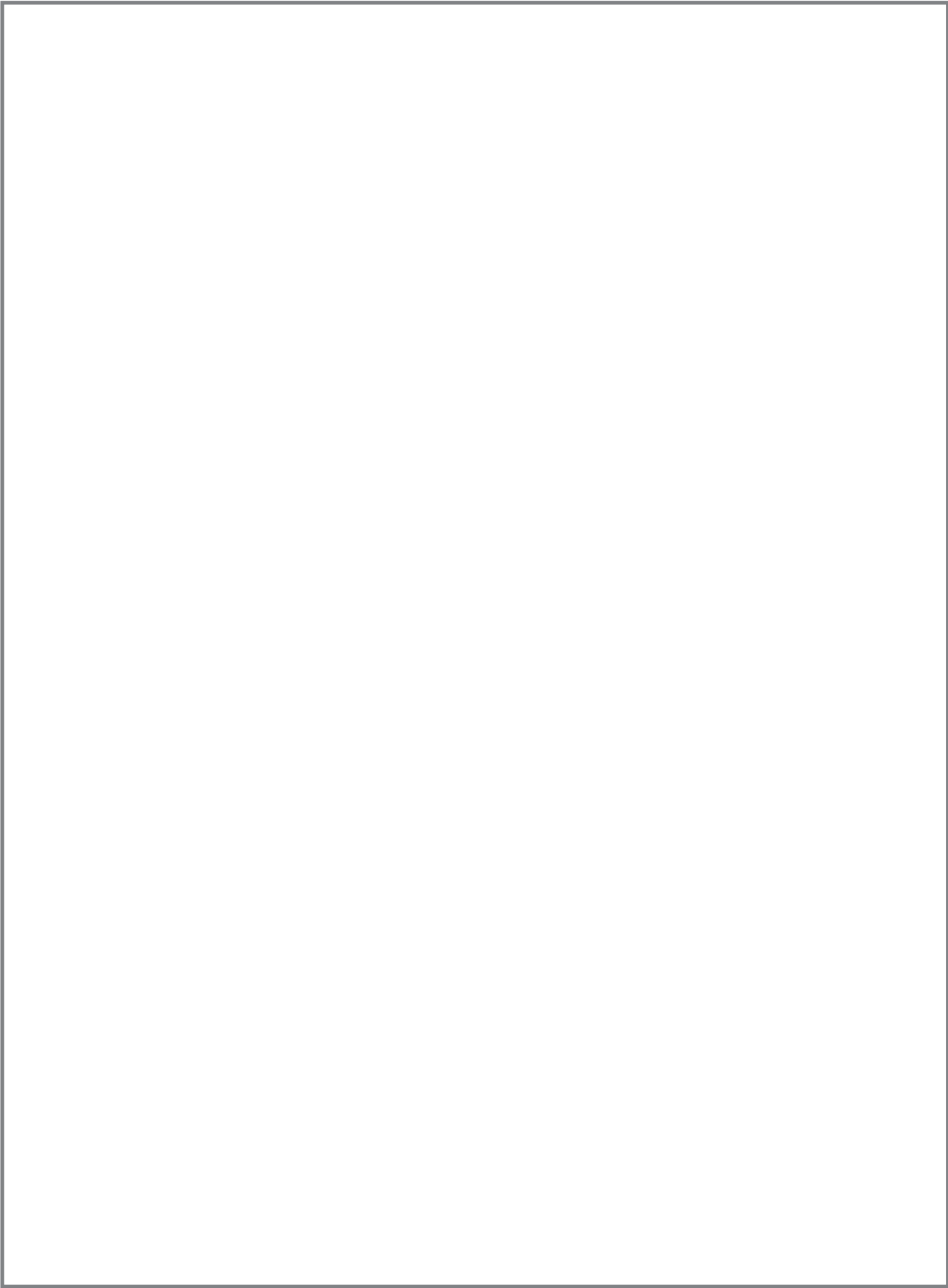
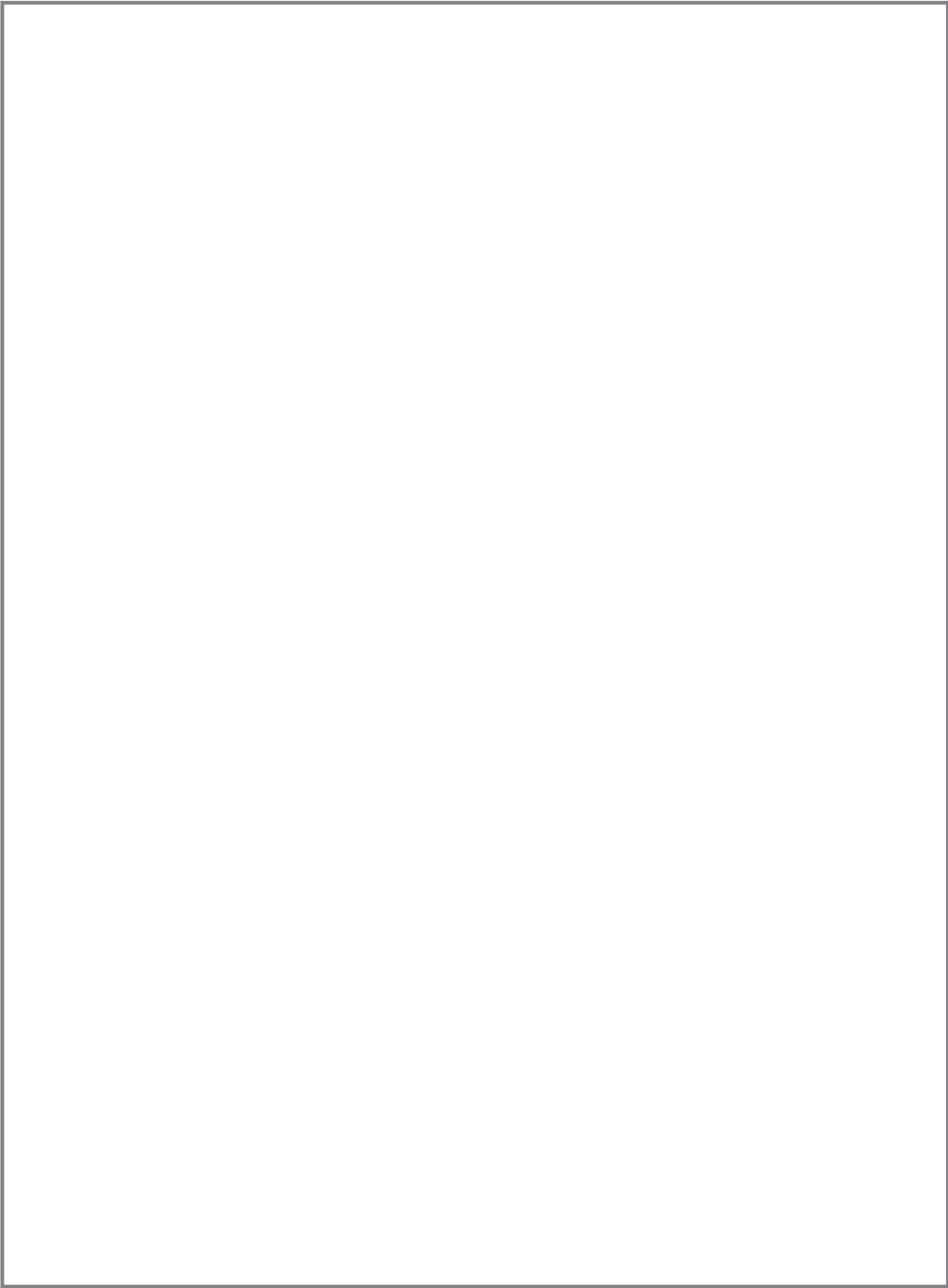


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Introduction

This document reports on the proceedings of a day-long meeting of researchers, practitioners and activists engaged in research on gay, lesbian, bisexual and Two-Spirit^a (GLBT-S) people's health in Canada. Twenty participants from across Canada, representing academic, public health and community organizations gathered at the McGill School of Social Work in Montreal. The goals of the meeting were to begin a process of interdisciplinary and intersectorial dialogue and to encourage the development and articulation of national priorities for research on GLBT-S health and health care. Participants discussed their current work, exchanged thoughts about current and future areas for research and action on GLBT-S health, explored gaps in knowledge on GLBT-S health and health care, and shared experiences about the various environments in which they work.

The report presented here is intended as a "work in progress". The purpose of this report is to serve as a starting point for an ongoing dialogue amongst researchers, practitioners and activists across Canada regarding priority areas for research on the health and well-being of GLBT-S people and communities. Due to financial and time constraints only a small group of people were able to participate in the day-long meeting, and thus influence the shape of the current report. It is the desire of the meeting participants to encourage others involved in GLBT-S health research and practice to join in our efforts to create national research priorities for GLBT-S health by reading and responding to the issues presented here, thereby adding their voices to this working draft document.

To this end, the organizers will be distributing this draft report as widely as possible in order to encourage open discussion, critical reflection, partnership and ownership of a "GLBT-S health research agenda" by GLBT-S people and communities themselves, as a fundamental principle of all research endeavours. It is our hope that this document will be continually adapted, in

an ongoing process, so that the diverse voices and perspectives of GLBT-S people and communities from across the country will be adequately reflected. The process of building this national research priorities initiative on GLBT-S health can serve to strengthen community capacity to advance knowledge and to influence national and regional public health policy so that the broader goal of equity in health care delivery for all GLBT-S people in Canada can be achieved.

Background

Up until recently, in both Canada and the United States, little documentation existed on the health needs and experiences of gay, lesbian, bisexual and Two-Spirit (GLBT-S) people outside the realm of HIV prevention and treatment for gay and bisexual men. As a result, health care practitioners and policy makers know very little either about the global health and well-being of GLBT-S people or about how best to develop appropriate, relevant, and affirming health and social services for them. In addition, while gay, lesbian, bisexual and Two-Spirit communities have much anecdotal information and personal experience to draw upon with respect to health and health care issues facing GLBT-S communities, they have little hard data with which to argue for the adaptation of health systems and institutions to better meet their needs. The situation is significantly more dire in Canada, where support for GLBT-S health research, and as a result, documentation on GLBT-S health, is almost entirely lacking.

The absence of documentation on the global health needs of GLBT-S people can be traced to the historic and current oppression they face within society generally and within health and social service institutions specifically. Because GLBT-S people have historically been socially defined within medical terms as mentally ill, the health care system has been one of the primary arenas through which control over their lives was exerted. As such, health professionals were often charged with the task of "healing" GLBT-S people from their so-called unhealthy same-sex

a Much evidence indicates that aboriginal people, prior to colonization and contact with European cultures, believed in the existence of three genders: the male, the female and the male-female gender, or what we now call the Two-Spirit person. The concept of Two-Spirit relates to today's designation of gay, lesbian, bisexual and transgender persons of aboriginal origins. Two-Spirit people traditionally held esteemed positions in their communities. The arrival of the Europeans was marked by the imposition of foreign views and values on aboriginal spirituality, family life and traditions. The missionary churches' views on sexuality, for example, created many new taboos. Many traditions, including that of the Two-Spirit were eradicated or at least driven underground from many (but not all) tribes of North America. This term of ancient usage is being reclaimed by many gay, lesbian, bisexual, and transgendered aboriginal people today to invoke remembrance of a time before colonialism and the exploitative contact with Europeans when Two-spirited people were honoured. (Meyer, Goodleaf and Labelle, 2000).

attractions through such means as electro-shock therapy or aversion therapy. Health research on GLBT-S people, where it did exist, was used as a tool to support the efficacy and appropriateness of these interventions. Given this history, it is no surprise that GLBT-S people have an uneasy relationship with and lack of trust of health research and of the health and social service system.

Although much has changed in the past twenty years with regard to the health care system's definition of homosexuality as pathology, health care professionals, institutions, policy makers and researchers continue to marginalize GLBT-S people. At best, the health care and social service system has attempted to create a semblance of "neutrality" in health policy, practice, and research based on the ideological belief that health care must be accessible to all, regardless of sexual orientation, and that health care services are best situated when they are developed with no special interest group in mind. However, in the experiences of GLBT-S people, this inattention to sexual orientation can be equally harmful, particularly in an environment that continues to be marked by homophobia and heterosexism. In terms of documentation and research, this neutrality has resulted in the almost total neglect of sexual orientation as a legitimate variable for consideration in studies on health and health care access.

Increasing pressure from GLBT-S communities on health care policy makers, providers and researchers has resulted in some changes, however marginal. GLBT-S people, as both health care consumers and health care professionals, continue to voice resistance to homophobic and heterosexist practices through the documenting of historic and current injustices, creating new avenues for articulating best policy and practice and developing expertise in GLBT-S health and health care issues. Both HIV/AIDS activist movements, gay and lesbian health organizations and women's health movements have helped to channel energies and focus expertise on the health needs of gay, lesbian, bisexual and Two-Spirit people. In Canada there is a growing interest in GLBT-S health and health care. There are, however, significant problems which limit the capacity of Canadian health activists, researchers

and practitioners to move forward on a national agenda on GLBT-S health and health care access. These include, but are not limited to:

- ◆ A paucity of Canadian research (published and non-published) on GLBT-S health and health care.
- ◆ Many of the research initiatives that are undertaken are done so under the auspices of localized community-based agencies who have little funding for national dissemination. These studies do not make it into academic health and applied health journals as the links between community research and university research are often very weak.
- ◆ Few opportunities for Canadian GLBT-S health researchers and practitioners to meet and exchange expertise.
- ◆ Lack of infrastructure support for the development of national working groups on GLBT-S health.
- ◆ Lack of communication/partnership development between community-based and university-based initiatives.
- ◆ Lack of focused support for GLBT-S research in health and allied health disciplines and academic environments.
- ◆ Lack of focused funding for research into the health of GLBT-S people.
- ◆ An absence of advocacy/lobbying initiatives at the national level with respect to GLBT-S health and health care.

These gaps have a significant impact upon the capacity of activists and researchers to communicate with each other, to develop national partnerships, to undertake research projects and ultimately to strengthen expertise on GLBT-S health. As a result, developments in the field of health with regard to best practices are slow and uneven.

A Framework for Health

The current initiative defines health from a broad perspective that incorporates the physical, psychological, emotional, social and spiritual components that contribute to health and well-being. The World Health Organization definition of health^b is most closely aligned with

^b According to the World Health Organization, "health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. It is the extent to which an individual or group is able, on the one hand, to realize aspirations and satisfy needs and, on the other hand, to change or cope with the environment".

the ideology of health as understood in the current context. Identifying health as a broad and holistic construct is particularly important when considering the lives and experiences of GLBT-S people. The experience of being gay, lesbian, bisexual or Two-Spirit in a homophobic society necessitates a broad view of health in which issues such as coming out, locating community and managing oppression are contextualized and understood as mental health issues. Utilizing this perspective facilitates the integration of an analysis of the health impacts of homophobia, heterosexism and marginalization upon the lives of GLBT-S people and the necessity of addressing physical, emotional, social, spiritual and psychological assistance when articulating recommendations for change, in line with population health theory and the adaptation of determinants of health to particular populations. Throughout this report, the terms health, health care and social service delivery, health accessibility, practice and policy should be understood to be inclusive, unless stated otherwise.

Purpose of Meeting

The meeting of researchers on GLBT-S health and health care has attempted to begin to address health and social service needs in GLBT-S communities in Canada, and the research development needed, in a broad way. Its goal was to facilitate a process of creative exploration on the question of how best to create and sustain an environment in which to support the building of expertise on GLBT-S health and health care in Canada. This includes the development of a critical mass of health care researchers and practitioners who are fully supported by academic and governmental institutions and who are driven by the multiple interests and concerns of GLBT-S communities across the country. This would facilitate the development of understanding with regard to the issues facing GLBT-S people and contribute to policy and practice initiatives that support their health and well-being and support research and practice endeavors. The current meeting set out to begin the process of building a national agenda on GLBT-S health and health care through the gathering together of participants in GLBT-S health research across Canada. Areas of discussion included:

- ◆ current Canadian GLBT-S health initiatives (see Appendix III)

- ◆ current American health literature related to GLBT-S people (see Appendix III)
- ◆ creation of avenues for collaboration on GLBT-S health and health care (including the development of a national conference and a Canadian journal devoted to GLBT-S health)
- ◆ development of a national centre on GLBT-S health research
- ◆ coordination of a clearinghouse for university and community based research
- ◆ identification of gaps in current Canadian research initiatives
- ◆ identification of regional variations in research/practice initiatives
- ◆ review of current climate for undertaking GLBT-S research
- ◆ creation of a national advocacy body on GLBT-S health and health care
- ◆ identification of potential partner agencies in various locations across the country
- ◆ development of a national group of interdisciplinary researchers/practitioners on GLBT-S health

This meeting was the first step in a process of consultation, research, and prioritization related to GLBT-S health issues in Canada. This beginning stage allowed for initial consultation with communities, researchers, and Health Canada, and directed attention to specific aspects for further consideration. The meeting re-enforced the notion that a broader process is needed in order to clarify, specify, and prioritize GLBT-S health research needs for Canadians.

The meeting was divided into two parts. The first half of the day focused on the sharing of recent research/practice endeavours and/or work in progress. Ten participants presented the results of research or practice initiatives in which they are involved. These are itemized in the appendix. The second half of the day was devoted to an open-ended exploration of issues, such as those related to: working environments, research priority areas, partnership development, the inclusion/exclusion of diverse GLBT-S people in research development, the relationship between research and action, practice-based research, ideas for collaborations, etc.

Report of Discussions

The following section reports on the themes and ideas that emerged from the open forum which took place in the afternoon. These themes/ideas are broadly divided up into three separate categories. The first relates to the environments in which GLBT-S health researchers work, particularly with respect to access to funding, difficulties with respect to avenues for publishing and support of GLBT-S research within academic environments. The second theme encompasses the reflections of participants on the guiding principles or philosophies which need to be emphasized in the development of research on GLBT-S health. Finally, the third theme reports on priority areas for research which were identified by participants, including perspectives which need to be included within these priority areas.

Environment for GLBT-S Research and Researchers

Throughout the day, participants reflected upon the environments in which they undertake research on GLBT-S health, both within academic and community settings. Many participants discussed the challenges they face in developing and producing research in the area and described environments that ranged from support to hostility. Those researchers located in gay and lesbian centres spoke of support received for the development of GLBT-S health research from colleagues and community members. Amongst university-based researchers, discussion focused upon the lack of support for research in this field among colleagues and departments. Participants from university settings shared experiences in which they faced homophobia and/or heterosexism including: the defacement of property, discouragement from undertaking research and teaching in the area, and discriminatory comments received by authors during the manuscript review process for publication.

All participants, whether in community-based or university-based settings, discussed the lack of financial support available for research on GLBT-S health, from both government and private sector foundations. The result of this lack of financial support is the decreased community capacity for evaluation and development of programs and increased difficulties with respect to advocating for policy and institutional changes to improve the health and well-being of GLBT-S

people. Further, much of the funding received to date has been channeled through HIV initiatives. This has meant that the lens through which research is undertaken is limited to the category of “men who have sex with men” in the context of HIV prevention. Participants emphasized that lesbian health and that the broader issues of gay men’s health are virtually ignored as a result. Therefore those researchers considering broader GLBT-S health issues are extremely under-funded.

Finally, all participants discussed the isolation they feel within their local settings. Participants pointed to the need to consider the climate in which GLBT-S issues are discussed as a central factor that can contribute to isolation. Participants also emphasized that the experience of isolation is considerably greater for ethno-cultural minority and Two-Spirit GLBT-S people who are often excluded in academic and community initiatives. Participants recommended that meetings, conferences, a web site, and a national clearinghouse are needed to address barriers, hostile climates and improve incorporation/legitimatization of knowledge. Participants also stressed the need for community/university alliances to reduce isolation, improve the grounded nature of research and ensure the inclusion of multiple agendas in academic environments. This was seen as essential to redress historic and current exclusion and marginalisation faced by diverse GLBT-S people and communities with respect to research on GLBT-S health.

The following quotes, taken from the discussion, highlight participants’ experiences and perceptions about current environments for undertaking GLBT-S research:

It’s been my experience over the past few years in doing this work, that we’re certainly not immune from discrimination. . . quite the opposite is true as we all know. We get all the range of reactions from people. . . from, someone defacing my door after doing a media interview, to the more passive “If you’re involved in this kind of work. . . remember: it can be taken away, because this is not something that the school or university sees as important.” So you have to do this work on top of, or outside of, what is normally expected of you and in environments which hold much risk. . .

I think that as a body we can close the gap when it comes to isolation, by extending outward to communities to share with us what they have, as well as give them

some options as to how they can put their work into some kind of constructive, working research model.

It's the impression that this isn't a legitimate area of research, and so it has to be hidden in other things, and gotten approved of in veiled ways. . . we've all been there in many different ways. . . and this is one of the first meetings on this issue, I think, that has been funded outside of HIV from the perspective of government funding, so that's an encouraging sign, but historically we haven't been able to do that.

My own research. . . what it really revealed was. . . a much greater concern was the climate and the silence of discussion on gay and lesbian issues, and the ways in which that happened, which were extremely subtle. . . one of the things that I think we really need to understand is how heterosexism actually works, and not make assumptions about how these things come to be. . . because sometimes well-meaning interventions can be directed at the wrong target. . . like maybe training isn't the key thing, maybe for instance, policy and the underlying structures have to be addressed first. . . I'm not saying not to do those things, but that there's a need for research to look at, to kind of identify and document and name the social relations that shape professional education and also social services.

The other thing that I'm concerned about is the absence of voice of lesbians and lesbian researchers. I agree too, that I think that not only from the point of view of the history of funding through HIV but also from the perspective of safety and lack of privilege. It's often harder for lesbians to come out in academic environments and do the work without facing the punishments. So how we support each other and, specifically, how we support lesbian researchers and academics and people to live and work in positive environments, I think would be important.

Guiding Principles

Much of the discussion during the open forum focused on guiding principles or philosophies necessary to the development of research on GLBT-S health. Participants stressed that issues such as representation, collaboration, theoretical and political orientation, and participatory research processes must be considered central to all research endeavours on GLBT-S health issues. Participants also stressed that it was essential to first outline the manner in which research should be carried out before it was possible to discuss

priority areas for research, in order to ensure that research was not experienced as oppressive and exclusionary by GLBT-S people themselves. Discussion centred on the philosophies and processes used by those around the table in their own research and practice initiatives with an emphasis on the following ideas: participatory processes in current research are necessary to redress oppressive research practices in health in which GLBT-S people were seen as "sick" subjects; building trust with individuals is essential to the research process; research should be tied to social and political change efforts in health and other arenas; multiply-located GLBT-S people have been dramatically under-represented in research on GLBT-S health, both as participants and as researchers. The issues facing diverse GLBT-S people must be considered in guiding principles in a way that recognizes their rights to self-identification and self-determination.

With respect to self-identification, participants stressed the importance of paying attention to the ways in which communities are labelled and defined in the current initiative. It was seen as important to remain open to change and to consider identity labels as fluid and changing concepts so as not to restrict or exclude people and/or communities in the process of defining themselves or of influencing research priorities. Further discussion/collaboration with multiply situated GLBT-S communities was suggested. It was also emphasized that for many communities, the process of research creation, definition and partnership takes time and that building trust between researchers, research bodies and communities is fraught with conflict and contradiction. Respecting pace and process is extremely important and should always be considered in work with marginalized people and communities.

Participants also had a discussion about the inclusion of transgender/transsexual people in the current initiative. Focus was placed on developing a process which is trans-positive and which sees itself as working in solidarity with trans communities. There was no conclusion put forward with respect to adding transgender/transsexual health research issues to the agenda. It is hoped that further discussion will be raised through dialogue about the draft report, including the means by which we can ensure solidarity with those working on transgender/transsexual health research in order to advance financial support and social change efforts.

With respect to social action outcomes of research, participants specifically suggested advocacy efforts should be aimed at micro-mezzo-macro levels, including: changes in health and social policy, inclusion of material/training programs in schools and professional and licensing bodies and changing policy, practice and attitudes in public health care, social service and educational agencies and institutions. Improvements in dissemination of information (particularly of results that are generated by community initiatives) were seen as central to supporting social change efforts.

The following is a list of ideas generated by participants, in no order of priority:

Diversity

- ◆ Equality work means exploring differences
- ◆ Self-identification, because of large number of categories and labels
- ◆ Awareness of whose voices are being included
- ◆ Further communication with populations (especially Aboriginal groups)
- ◆ Care taken with terminology
- ◆ Need clarity on inclusion of Two-Spirit people, Aboriginals - enough confidence in term?
- ◆ Pacing and process
- ◆ Don't assume knowledge
- ◆ Awareness of specificity of groups
- ◆ Recognize diversity in Canada
- ◆ Recognize self-determination of communities
- ◆ Acknowledge trans-gender and trans-sexual issues, and solidarity with these groups
- ◆ Some disagreement with including trans issues, because of significant differences, unique issues in these populations

Tying Research to Social Action

- ◆ Need policy, mezzo, micro level activities
- ◆ Need issues included in school mission statements
- ◆ Changes in attitudes - how to do this?
- ◆ Education for GLBT-S populations, to advocate for selves
- ◆ Training

- ◆ Dissemination of basic information to professionals
- ◆ Education for communities
- ◆ Focus on advocacy
- ◆ Adult learning/education
- ◆ Focus on university training
- ◆ Licensing bodies - set and improve standards
- ◆ Global approach

The participants had many and varied ideas and suggestions as to the guiding principles for research. The following section summarizes some of the statements made in this section of the discussion:

Another thing is to strengthen the infrastructure in community organizations, so that people within community organizations gain appropriate research skills, and take part in a meaningful way in collaborations with researchers who have the more academically-legitimized roles as researchers... and by strengthening infrastructures, I mean continuous spending, operational funding and so on, that's part of it.

I think that it's really important, for looking at gay-lesbian-bisexual-Two Spirit health, that there be an equitable priority between gay, lesbian, bisexual and Two-Spirit people... because, it's easy, especially given the history of a lot of funding and priority going to HIV prevention among gay and bisexual men... for the money to continue in that direction. I think that it's important that there be an explicit commitment to equity for funding and priority with lesbian health, bisexual women's health and Two-Spirit health...

One of the things about marginalized communities is that we have to find creative ways, and we become resilient and we have to survive. So there's a lot of what we describe, back home, as indigenous knowledge. It's the things that we know, that we've learned from experience, that we've learned from mentors. It's the practices that we have, it's the knowledge that's not legitimized within policy frameworks at the provincial level, federal level or service level, which is why I think we're looking at these lists... I think we have an opportunity within a research framework to tap into that indigenous learning, that's very culturally-based and that will be diverse, and we have a lot to learn from each other around that... I think the notion of understanding ourselves as researchers and our

communities as learning sites, so that we understand fundamentally that gays and lesbians who try to access the world and try to access health, whether that's from peers or systems or whatever... it's fundamentally a learning reflection and a strategic process. So, if we begin to understand our work and the research we produce as being part of a learning site... part of a living organism, I think that can make it go farther.

... we're all here wanting to make some change, and we can publish some of the best research, but we also need to make sure it results in change, involving the community and not losing sight of "how do we put this into action?" So it's not just the research, but also the action... and whether that be education or developing the community or whatever... to keep that in sight.

Priority Issues for Research

Several areas were suggested as priority areas for future research. It is important to note that the participants do not consider this list to make up a definitive "research agenda". Instead, this list is meant only to generate further discussion about themes, areas of concentration and current gaps in research. Also, several of the suggestions listed below relate not to areas for research but instead focus on areas through which research can be supported or enhanced. For example, participants discussed needing to improve environments to encourage inter-provincial and interdisciplinary research collaboration, dissemination and marketing of research, and training future practitioners in health in order to raise awareness of the importance of considering GLBT-S health as an important issue for practice and research.

Gaps in research on GLBT-S health were identified. For example, participants stated that, while some documentation exists on the impact of homophobia and heterosexism on health, there is far less information available on best practices. There is a need to focus on what works and in what ways practice can be adapted/transformed. Another area identified centred on research that considers the experience of professionals with respect to coming out.

Participants outlined several methodologies which would facilitate a wider range of discussions and community involvement from the bottom-up including action research and participatory models.

The following is a list of ideas generated by participants, in no order of priority:

Building Support for GLBT-S Health Research

- ◆ Due to isolation, need meetings, Web site, national clearinghouse
- ◆ Enhanced training of professionals, faculty, and students
- ◆ Schools need to include GLBT-S issues in curriculum at all levels
- ◆ Look at climate in which GLBT-S issues are discussed
- ◆ Research to look at the social relations that shape education
- ◆ Funding organizations
- ◆ Strengthen infrastructure of GLBT-S organizations (increased and consistent funding)
- ◆ Canadian Institutes of Health Research (CIHR) needs to be involved
- ◆ Increase collaboration between communities and universities
- ◆ Publication
- ◆ Networking
- ◆ Increased multi-disciplinarity
- ◆ Enhanced mentoring
- ◆ Development of educational modules
- ◆ More partnerships between professionals and community
- ◆ Need to create a journal of GLBT-S health issues
- ◆ International meetings
- ◆ Focus on action
- ◆ Need national coordinator
- ◆ National directory of professionals
- ◆ Annual meetings
- ◆ Increased resources
- ◆ Multi-centre collaboration
- ◆ Presentation of research
- ◆ Need data for policy development
- ◆ Need common understandings between stakeholders
- ◆ Clarify roles in project development
- ◆ Lobby and educate policy makers, funders, etc.

- ◆ Challenge agenda of government
- ◆ Assert importance of GLBT-S issues
- ◆ Create discussion document(s)

Gaps in Current Research

- ◆ Focus on smaller cities, towns, rural communities
- ◆ Aging
- ◆ Experiences of professionals
- ◆ Best practices
- ◆ Involvement of young people
- ◆ Inclusion of ethno-cultural factors
- ◆ Costing for prevention/intervention
- ◆ Population health approach
- ◆ Methodologies to promote inclusion of previously excluded people, including other forms of knowledge-building in communities
- ◆ Move from AIDS to health promotion

The following quotes highlight areas identified in the discussions on priority issues for research:

One of the things that I hope we can build upon is putting pressure on the Canadian Institutes of Health Research to accept a body of GLBT-S researchers, and to make sexual orientation a fundamental priority of health research... maybe this could be the beginning of putting something together which would influence the CIHR to begin to fund our work.

I think we should really enhance our role as mentors, whatever discipline we're in, whether we're researchers or policy-makers or clinicians or academics... I find that colleagues do want to know, but they want to know who to ask. And something that I think would be very helpful would be for us to try to establish, as part of a clearinghouse, a national directory of people such as ourselves and other people we can name, who are doing the work, who would be willing to mentor one-on-one or willing to do a lecture if asked, or that kind of outreach work. So I was sort of thinking of how we would operationalize this and if we were to develop some kind of forum for this directory, we'd have different categories of how people wish to be involved... whether they'd be willing to give a talk, whether they'd be willing to take a phone call around a particular question or issue... So, I think it's something that's fairly do-able and I think something that would really help consolidate our efforts.

Another thing that came to me was... to be validating and recognizing and drawing on participatory methodologies of research that have been developed through women's health, HIV prevention and HIV work with marginalized communities over the past 15-20 years, and also international development work. To be drawing on methodologies developed through that... because we'll talk a lot about what issues need to be addressed, but there's not a lot of talk about methodologies... and to widen those methodologies and to recognize what's been done before by people working in communities... directly related often times to queer health, but not necessarily called that.

I think there's a big difference between behaviour change and attitude change, and that policies can also demand behaviours, which I think needs to be explored... because I don't think that academic institutions have really addressed the issue of acceptable or appropriate behaviours in their policies, and that we should at least be able to document and see where people are moving on that. I think that you can have correct behaviour without having the right attitudes or correct attitudes, but if you're behaving properly sometimes you change your attitude over time as well. I'd like to see some kind of development of educational modules which address not the knowledge issue so much, but the attitudinal issues that we want to have addressed in the academic centres. And I'd like to see an extension of the interdisciplinary HIV/AIDS course or new ones being funded to develop... which are involving the kind of goals which Health Canada set forward in the Primary Health Care Reform... the interdisciplinary activity... that we've got true interdisciplinarity. I mean there's a nice mix here around the table, but if you go back to the school of social work or nursing or the faculty of medicine... how many of the courses are truly interdisciplinary? So, I'd like to see true, funded modules which are interdisciplinarily based, as far as the educational system is concerned.

I have another mission, it's to try in the other universities, try to develop a new network, research network... they are able and they want to work with community organizations, but not with the idea to publish for them. I think it's a new way, a new paradigm to work together, and I think it will be a really great year, I think the momentum is great for that. So maybe, I don't know if at Québec or at McGill it can be possible, but at UQAM I think they are more open on this way. So, I think the academics

should have to work on this kind of recognition... so the counterpart of that it's if you work with the community, you have no time to publish, and you're nothing. So I think if we want to develop this partnership... and it's really important with gay health issues, I think... we have to be supportive in the transfer of knowledge, but not in the scientific way necessarily. But really, do you realize all that we have heard about this morning, and we know nothing about this, because we have no time to publish! So, I think we have to, in the agenda, I think we have to work on this.

I think we need to be really cautious that we don't end up with research residing only in the larger communities, 'cause I think that the realities of life on the prairies and in the Maritimes are very substantially different from Toronto, Montreal, or Vancouver.

... one of the things that we need to work on, which I think needs to be a priority, is lobbying and educating policy-makers, decision-makers, those who control the purse-strings. While I agree that we need to look at what the government's agenda is, I think we need to change the agenda. I'm tired of always having to do this work by sneaking it in the back door, 'cause you can't do good work that way! You always got project-officers over your shoulders, who are often very supportive, but they've got people over their shoulders up to the minister. So I think that one of our first initiatives needs to be lobbying and educating those that make decisions and hold the purse-strings in this country, that this is an issue of significant importance and the time to deal with it is now.

Next Steps and Recommendations

Participants felt that the meeting was quite successful for a number of reasons. First and foremost, participants stated that having the opportunity to meet other researchers, practitioners and activists from across the country doing research on GLBT-S health facilitated the building of new networks/collaboration and reduced isolation. For many it was the first time that they had an opportunity to share collaboratively with their peers from interdisciplinary fields and it reinforced, for participants, the need to create more opportunities of this nature in order to receive feedback and explore common/divergent ideas.

Several participants commented that this was the first time that they had participated in a national meeting on GLBT-S health which was organized

outside the lens of HIV. This created increased room for consideration of lesbian health issues and enabled a broader discussion of gay men's health issues to take place.

Participants also expressed satisfaction with being able to share ideas amongst anglophone and francophone researchers. It was recognized that more work needs to be done to include people of colour and Two-Spirit people around the table in order to enhance equity and ensure the inclusion of diverse GLBT-S health issues in the articulation of research priorities.

It is hoped that this document can be used as a means of gathering information from as broad a constituency as possible, including academic researchers and community activists in order to ensure that priorities reflect regional, gender, ethnicity, race, disability, age and other issues of diversity within GLBT-S communities.

To this end, participants stated that the draft report should be as widely distributed as possible. Participants agreed to support these efforts by either forwarding the e-mail addresses of colleagues that they feel should receive copies of the report for commentary or forwarding the document themselves. People will be encouraged to provide feedback on the content of the text. We also hope to upload the draft report onto McGill's School of Social Work's Project Interaction Web site to facilitate collaboration and review.

Participants stated that this working document should be used as a tool to begin to influence the public policy agenda on health research in order to make it more reflective of the concerns and issues facing GLBT-S people and communities. For example, it can be used to advocate for the development of a Canadian journal on GLBT-S health and to affirm the need for the Canadian Institutes of Health Research to consider sexual orientation within their mandates and priorities for research funding. Bill Ryan and Shari Brotman, as meeting organizers, were given the mandate to move these issues forward based on the dialogue from the day-long meeting and to continue to discuss process and potential outcomes with Health Canada.

Participants suggested continuing the dialogue and process of networking among GLBT-S health researchers, practitioners and activists through the development of a national body or working group that could plan national and regional meetings on GLBT-S health research. This would ensure that the momentum gained on this day would not be

lost. In order to do this, the following issues were named:

- ◆ Find a name for a national body
- ◆ Create a mission statement
- ◆ Clarify goals
- ◆ Undertake strategic development at the national level

Discussions will continue to take place among participants, organizers and Health Canada in order to identify ways in which to facilitate the development of such a national body dedicated to GLBT-S health research.

In closing, we wish to say thank you to all those who contributed to the discussions on the day of the national meeting and welcome those who are just joining us by reviewing this document. We hope that you will read this document carefully and add your perspectives to it by providing us with feedback as to process, environment for support and priority areas for research.

To Reach Us:

If you would like to be put on a list for further communication/dissemination of information, please e-mail or write to us giving us your name, address, phone number, e-mail address, affiliation and areas of research/practice/activism in gay, lesbian, bisexual and Two-Spirit health and health care.

Please send comments/suggestions/information to:

Bill Ryan and Shari Brotman
Gay, Lesbian, Bisexual and Two-Spirit Health
Research Initiative
c/o McGill School of Social Work
3506 University Street, Room 300
Montreal, QC
Canada H3A 2A7

shari.brotman@mcgill.ca

Appendix I: Participants

The following is a list of affiliations and areas of interest of the participants who attended the day-long meeting in Montréal.

Barry Adams:

Department of Sociology and Anthropology, University of Windsor. Barry is a member of the Gay Men's Health National Reference Group. He teaches a course in gay and lesbian studies at the University of Windsor, and has done quite a lot of work on gay and lesbian movements around the world, and in HIV and AIDS studies, both issues of living with HIV and prevention.

Jane Allen:

AIDS Coalition of Nova Scotia. The AIDS Coalition has a long history with community-based research and is currently in the process of setting a research agenda for gay men's health in Halifax.

Brent Bauer:

Doctoral Candidate, Department of Political Science, University of Montréal. Brent is a member of the board of directors of Égale, and chair of the Research Committee. Égale has been increasingly interested in being involved in health and education issues and has been a partner in the Access to Care study led by Bill Ryan and Shari Brotman.

Ian Bowmer:

Faculty of Medicine, Memorial University. Ian is primarily concerned with infectious disease and has spent a lot of time, in his primary practices, with persons with HIV. He is also currently the Dean at the University, and is interested in interdisciplinary teaching approaches and the introduction of aspects of health into the curriculum, which don't normally get covered. He has been involved in several programs in terms of therapeutics and self-care approaches that Health Canada has been supporting.

Shari Brotman:

School of Social Work, McGill University. Shari is an Assistant Professor at the School. She primarily does research on health care access and marginalized communities, including GLBT-S communities and ethno-"racial" minority communities. She also has an interest in gay and lesbian aging, both with respect to elders themselves and their caregivers. She has done some research on identity formation among

ethnically-identified lesbians and is interested in aspects of identity and multiple oppression.

Tony Caines:

Toronto Public Health. Tony is a member of the National Reference Group, for the revitalization of gay men's health, looking at HIV prevention within the broader context of gay men's health. Within Toronto Public Health, he is presently interested in the re-organization and restructuring of its position in HIV prevention. In addition, he is concerned about the inclusion of people of colour in research endeavours.

Michael Chervin:

Coordinator, Graduate Diploma in Community Economic Development, Concordia University. Michael is the chairperson of Project Interaction which is a gay/lesbian/bisexual/Two-Spirit initiative at the McGill School of Social Work and has been active with the ethno-cultural communities project at Séro-Zéro, which is an HIV prevention organization for men who have sex with men and gay men.

Bill Coleman:

Psychologist, STD/AIDS Control, BC Centre for Disease Control Society. Bill has been at the clinic for approximately 10 years. He was involved in the AIDS Impact Conference two years ago in Ottawa and is part of a community-based research group in Vancouver.

Michel Dorais:

École de service social, Université Laval. Michel is a professor at the Social Work School at the University of Laval. He works mostly on gender studies and queer studies and has worked with the team on the adaptation of social services for homosexual and bisexual clients with Bill Ryan for 10 years.

John Fisher:

Director, Égale. Égale is a national group serving lesbians, gays, bisexuals and transgendered people across the country. The issues affecting Égale's members range from violence and suicide issues, to general health access, well-being issues, HIV, etc... and they are very interested in supporting the development of research to help serve the needs of their members.

Gens Hellquist:

Executive Director, Gay and Lesbian Health Services, Saskatoon. Gens sits on the National Reference Group, which is a committee that is devising a report for Health Canada on strategies around HIV prevention that takes into context the broader health issues in the gay male community. Gay and Lesbian Health Services, Saskatoon is hosting a national gay and lesbian health conference in Saskatoon on Labour Day weekend, September 2001. Gens's interests are service delivery and research issues around service delivery. He is also interested in identity issues.

Karine Igartua:

Department of Psychiatry, McGill University. She is medical co-director of M.U.S.I.C. (McGill University Sexual Identity Centre), the only Canadian psychiatric clinic devoted to promoting the mental health of gay, lesbian and bisexual patients. The centre is devoted to clinical care, research and training of health professionals. Karine's main research interest is the impact of internalized homophobia on health.

Danielle Julien:

Department of Psychology, Université du Québec à Montréal. Danielle's field is family psychology. She has been studying couple relationships for the last 10 years, particularly gay and lesbian couples. Now, she is interested in family issues; the relationship of these couples with their own families of origin, and their own children. She is particularly interested in the new generations of the "Gayby Boom"; what are the links, in particular the context for development of these children, and the gender issues involved in those, and also the impact of having children for gays and lesbians on their relationship with their own family.

Fiona Meyer:

Social Worker, Researcher, Diversity Educator. Native Women's Shelter, Tracom Crisis Centre, QC. Fiona has researched the health and social service needs of Two-Spirit people. She works with video, storytelling, mask, drama and the arts in community wellness. Recently she facilitated a workshop for the Urban Aboriginal AIDS Awareness Program, which used the arts to explore the theme of "taking care of ourselves/taking care of the world". She sits on the steering committee of Project Interaction, the Gay, Lesbian, Bisexual and Two-Spirit Initiative of the McGill School of Social Work.

Brian O'Neill:

School of Social Work and Family Studies, University of British Columbia. Most of Brian's research has been around gay issues in social work education. Also, he is interested and starting to do some work in access to mainstream health and social services for gay men.

Joanne Otis:

Department of Sexology, Université du Québec à Montréal. Joanne has worked with the gay community since 1995. She works primarily with the Omega Project and with Bill Ryan on the evaluation of the Safe Spaces Project.

Allan Peterkin:

Psychiatry and Community /Family Medicine, University of Toronto. Allan works out of Mount Sinai Hospital, in the clinic of HIV-Related Concerns. It is the oldest psychotherapy clinic in the country for people living with HIV and their families. He does general psychiatry as well, which means that he also has a private practice with a lot of gay and lesbian clients.

Brenda Richard:

School of Social Work, Dalhousie University. Brenda works primarily in the areas of violence and crimes against gay and lesbian people, and also violence within relationships. She also has a strong interest in a couple of historical periods; the 20s, 30s and 40s and the McCarthy era, in terms of the impact that those eras had on the promotion of particular images of people, and the consequences that those images had, not only for the people who received them, but also for the people who were responsible for promoting them.

Bill Ryan:

School of Social Work, McGill University. Bill's work primarily involves sexuality, sexual orientation, health care, HIV prevention, care and policy development, and international social work. He has been giving training and doing research on sexual orientation issues for the past 15 years.

Helen Slade:

Community Health Coordinator, Health Services, University of Toronto. Helen's work is with students in Health Services. Health Services at the University of Toronto has been trying to advance and improve the services to lesbian, gay, bisexual, transgendered, questioning (LGBTQ) students and to the large "questioning" community at the university.

Pierre Tremblay:

Pierre Tremblay: Independent researcher associated with Richard Ramsay (University of Calgary) and Chris Bagley (University of Southampton). Pierre specializes in suicide problems related to gay and bisexual male youth. He is currently preparing three papers, two are on the effects of harassment (especially anti-gay harassment) in adolescent suicide and one on the

intersection of homosexuality and child sexual abuse.

Susan Hicks and Xania Gordon:

Health Human Resources Strategies Division,
Health Policy and Communications Branch,
Health Canada representatives were observers.

Appendix II: Summary of Presentations

The morning portion of the meeting was designated for research presentations. Several of the invited researchers presented current and recent projects and findings, dealing with various aspects of gay, lesbian, bisexual, and Two-Spirit (GLBT-S) health issues in Canada. Presenters included:

Barry Adams, who discussed the results of his research with gay men who practice unsafe sex, the reasons why they may engage in unsafe sex, and the possible consequences;

Shari Brotman, who briefly outlined four research and educational initiatives undertaken by herself and Bill Ryan on health care access among gay, lesbian, bisexual and Two-Spirit people and communities, including one project specifically addressing gay and lesbian aging;

Michael Chervin, who detailed the program activities of Project Interaction, a gay, lesbian, bisexual and Two-Spirit initiative of the McGill School of Social Work;

Michel Dorais, who discussed his new book, "Mort ou Fif", which is a result of his research on the problem of attempted suicide in relation to adolescent gay men in Quebec;

Karine Igartua, presented data from her research correlating internalized homophobia to depression and anxiety in both clinical and community samples.

Danielle Julien, who discussed family counselling issues unique to gay men and lesbians;

Fiona Meyer, who discussed the unique history and contemporary needs of Two-Spirited individuals and the impact of homophobia and heterosexism on these individuals;

Joanne Otis, who discussed the results of the OMEGA cohort (sex between men in Montreal);

Allan Peterkin, who discussed work that he is doing with narrative therapy groups and HIV positive individuals;

Bill Ryan, who reviewed the Quebec Ministry of Health and Social Services training program on adapting practice to meet the needs of gay, lesbian and bisexual clients;

Pierre Tremblay, who presented data linking harassment (based on race, gender and sexual orientation) and sexual orientation to suicide attempts among young gay men and lesbians.

Health Promotion and Population Outreach in the Black and Caribbean Canadian Community

Condensed from the original paper prepared for:

*Health Care System Division
Health Promotion and Programs Branch
Health Canada, Ottawa*

April 2000

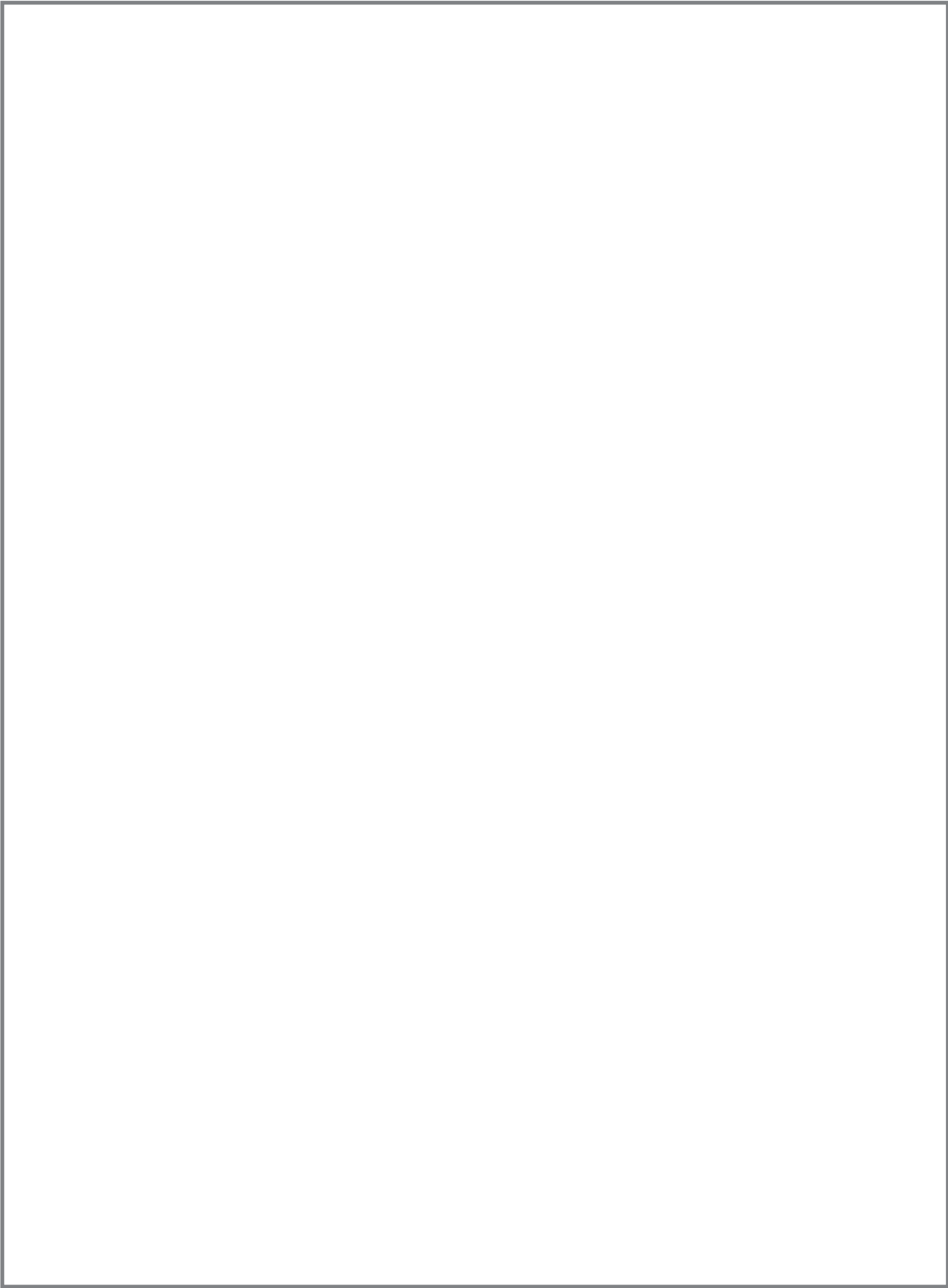
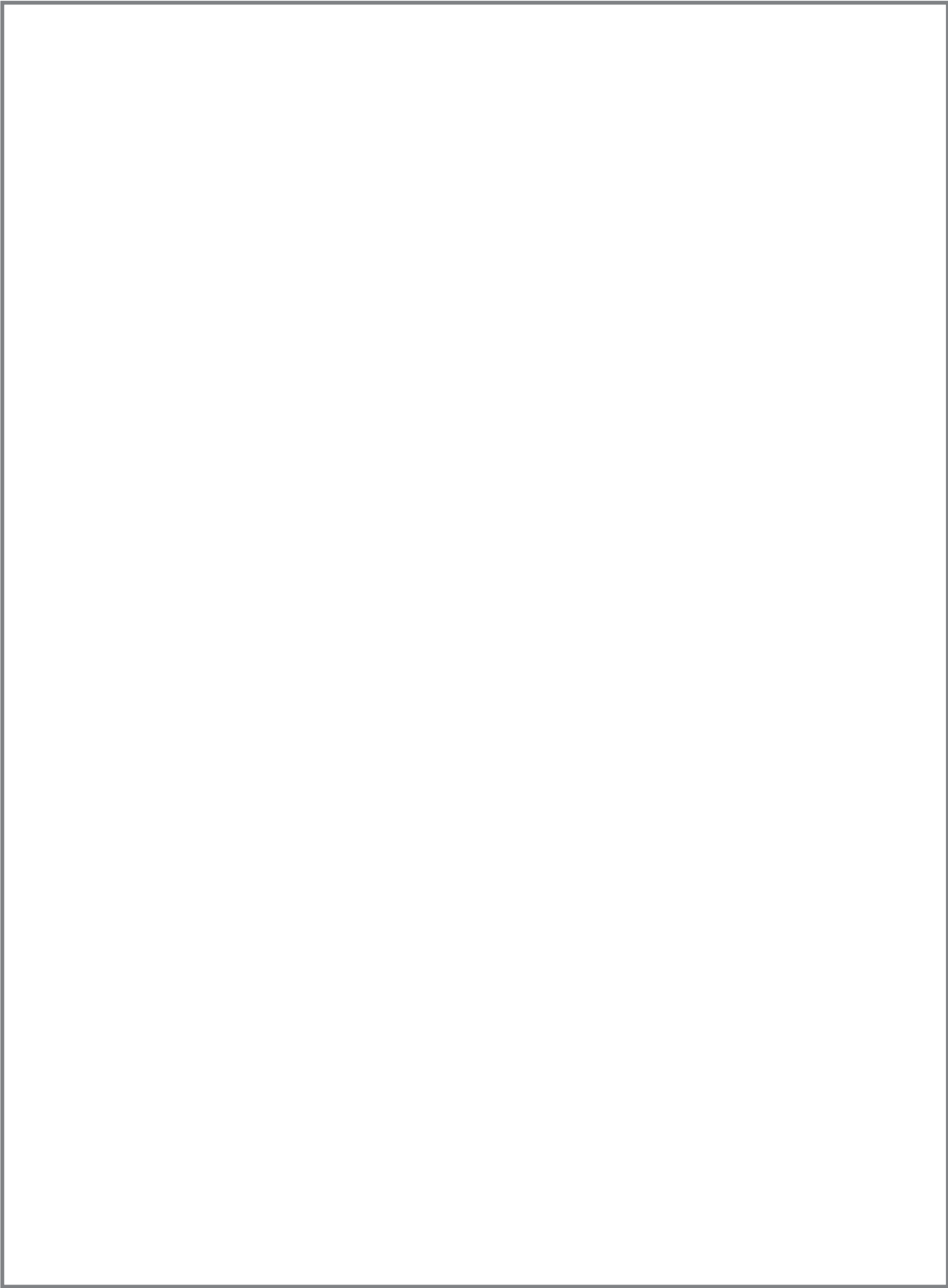


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Executive Summary

Introduction

The Canadian Centre on Minority Affairs Inc (CCMA), under contract to Health Canada, conducted this study on Health Promotion and Population Outreach in the Black and Caribbean Canadian community. The CCMA is a non-governmental organization promoting social development and other empowerment initiatives for interested sectors of the Black and Caribbean community in Canada. The black population in Canada is estimated to be 504, 290. The community is economically disadvantaged and under served in terms of health care.

The purpose of the study was to provide a preliminary view of health care issues and needs in the Black and Caribbean community in Canada. Study objectives were as follows:

- ◆ Identify and conduct a comprehensive review of published and unpublished literature on the health needs of Black and Caribbean communities, with a focus on access to health.
- ◆ Collect data / information, through consultations, on the issues affecting health care access and delivery to the Black and Caribbean Canadian community.
- ◆ Prepare a final report with appropriate recommendations to Health Canada.

Methodology

Due to its preliminary nature, qualitative methodologies were used in this study. These included a literature review on the health needs of Black and Caribbean communities and consultations with 32 key people and organizations (see Appendix A). The study's budget limited its scope to a literature review and consultation with the Black and Caribbean community in Ontario and Nova Scotia, only. Budget constraints also did not allow for a survey of the general Black and Caribbean community.

The 32 key informants were selected on the basis of their understanding and knowledge of health and related issues in the Black and Caribbean community. A standardized questionnaire was used to interview key informants. The data

collected were organized into standardized categories for analysis. The research was conducted by two researchers. District Health Councils in Ontario and organizations in the Black community in Halifax were also contacted to establish links and obtain information about their activities.

Study Findings

The study identified societal risk factors such as racism, adjusting to a new society and unrealized expectations as the main sources of stress in the community.

Stress is recognized as a major factor in mental health and other illnesses and diseases. Systemic discrimination within health care institutions and the lack of culturally sensitive services for the community were also identified as impediments to access by members of the Black and Caribbean community. In addition, the resources of mainstream voluntary organizations have not been made available to the community.

The most recent census data indicate economic disadvantage within the Black and Caribbean community. The health care effects of economic disadvantage are compounded by systemic discrimination in health care institutions and health care services that fail to recognize the community's unique cultural and physical characteristics. In addition, the focus on language within multicultural health care tends to exclude the needs of the Black and Caribbean community from consideration.

Key informants from the Black and Caribbean community emphasized that unfamiliarity with the Canadian health care system means that members of the community are not using the system in the most effective way. They also regard the community's reliance on home remedies and reluctance to seek medical care unless seriously ill as factors in the under use of the health care system. The influence of spiritual beliefs on approaches to prevention and treatment identified in the literature review and community consultations indicate the need to factor them in the development of health care projects. The literature review highlighted the lack of

quantitative and qualitative studies related to the health of the Black and Caribbean community in Canada. Study results also identified special health information and service needs of different segments of the community such as teens, youth, adults and seniors in relation to lifestyle, mental health, medical check ups, long-term care, etc.

Black and Caribbean organizations have been established to respond to the community's need for health information and services. However, most are under-resourced. This hampers their ability to provide effective and well-coordinated services. Parallels were drawn with the Aboriginal community, which has received funding to respond to its needs.

Consultations with key informants indicated that many health conditions are having a significant impact on the community.

Key informants in the Black and Caribbean community suggested that the following actions should be taken to address health issues:

- ◆ Qualitative and quantitative research on the demographics of the population and socio-environmental prerequisites, health conditions within the community and program and service needs
 - ◆ Establishment of collaborative networks and creation of a skills inventory and database of research information specific to the community
 - ◆ Provision of information on culture, beliefs and values to health professionals about the Black and Caribbean population they serve
 - ◆ Increasing representation of blacks in the health sector
 - ◆ Conducting culturally appropriate outreach to educate and raise awareness about prevention and treatment of health conditions
- ◆ Inclusion of community members in the policy decision making process
 - ◆ Building capacity through community empowerment and institutional supports

Recommendations

The following recommendations are based on findings from the literature review and consultation with key informants from the Black and Caribbean community:

1. Participation of the Black and Caribbean community in the health care policy development process:
2. Capacity building within Black and Caribbean organizations to enhance their ability to be effective and coordinated in helping to meet the needs of the community. Strengthened organizations would be in a better position to collaborate on initiatives to improve the health of the community. This would contribute to the sustainability of health care initiatives.
3. Provision of support and resources to assist organizations to undertake local projects that are consistent with the health priorities of the Black and Caribbean community.
4. Funding of an organization to enhance its organizational capacity to advocate on behalf of the community by:
 - a) Representing community interests and views
 - b) Providing a national forum
 - c) Connecting with other stakeholders and communities across Canada
 - d) Mobilizing participation and action on health within the Black and Caribbean community.

Introduction

Background

The Canadian Centre on Minority Affairs Inc (CCMA), under contract to Health Canada, conducted this study on Health Promotion and Population Outreach in the Black and Caribbean Canadian community. The CCMA is a non-governmental organization promoting social development and other empowerment initiatives for interested sectors of the Black and Caribbean Community in Canada.

For the purpose of this study, the Black and Caribbean community in Canada consists of Indigenous Blacks with several generations of Canadian history, Caribbean immigrants and their children, African immigrants and their children, and people of African descent from other countries who have migrated to Canada. According to the 1991 Census, the Black population in Canada is 504,290. However, due to definition and other issues, it is estimated that the population numbers in Ontario and Quebec are under estimated by 40% (McGill Consortium for Ethnicity and Strategic Social Planning, 1998). As a result of immigration mainly from the Caribbean, the Black and Caribbean population has doubled in the last 20 years. The community is younger than the general Canadian population. Halifax has the highest percentage of Black elderly.

The black immigrant population is concentrated in Toronto and Montreal. Halifax has the highest percentage of Canadian-born blacks. In Toronto, immigrants into the community were mainly from the Caribbean until the 1988-91 period when large numbers of African immigrants settled in Toronto (Canadian Centre on Minority Affairs, 1999). The Black and Caribbean population in Toronto is estimated to be 172,000 using Statistics Canada data, but could actually be 247,000 due to under-reporting (Canadian Centre on Minority Affairs, 1999).

The Black population in Canada is 504,290. However, due to definition and other issues, it is estimated that the population numbers in Ontario and Quebec are under estimated by 40%.

Based on Statistics Canada data, the Black and Caribbean community make up 25% of the racial minority population in Toronto and is the second largest racial minority community in the city.

There is a higher percentage of single parent families in the Black population than in the general Canadian population. In spite of their higher level of poverty due to single parent status, a smaller percentage rely on social assistance payments than others in a similar situation. In the Black and Caribbean community in Canada, due to patterns of migration, there are far more women than men than is the norm in the general Canadian population. A higher percentage of the community's population is under 15 years old compared to the general population, while the percentage of the population above 65 years of age is lower.

They also experience higher levels of unemployment and a significant portion lives below the poverty line. Overall, Blacks tend to be more disadvantaged than most other racial minority communities and much worse off than the population as a whole (McGill Consortium for Ethnicity and Strategic Social Planning, 1998).

Although overall levels of education are similar to the Canadian population and higher in the case of immigrants, Blacks are under-represented in higher paying occupations.

To assist in understanding the implications of an integrated health system and its impact on the Black and Caribbean Canadian community, the CCMA conducted a preliminary review and analysis of issues. The terms of reference of the study focused the research in Ontario and Nova Scotia. The study began in mid-February 2000

and was completed in May 2000.

Although overall levels of education are similar to the Canadian population and higher in the case of immigrants, Blacks are under-represented in higher paying occupations.

Methodology

Study methodology consisted of a literature review on the health needs of Black and Caribbean communities and consultations with key people and organizations with understanding and knowledge of health and related issues (see Appendix A). The project also outreached to District Health Councils in Ontario and organizations in the Black community in Halifax to establish links and obtain information about their activities.

Literature Review

A comprehensive review of published and unpublished literature on the health needs of Black and Caribbean communities was undertaken. The literature review focused on Canadian sources of information in the late 1980s to the current period. Both paper and electronic searches were conducted using branching techniques.

See the Bibliography at the end of the report for a list of information sources that were identified and reviewed.

Literature Review

The review of literature for this study involved an extensive search of published and unpublished sources of information on health and related issues in the Black and Caribbean Canadian community (see Appendix A). The literature search revealed the lack of quantitative data and the existence of a limited amount of qualitative information on health issues affecting the Black and Caribbean community in Canada. This contrasts with the wealth of information on the health of the Black community in the United States. In Canada, the focus is on multicultural health, and the issues affecting the Black and Caribbean community tend to receive limited attention.

The literature review includes descriptive and evaluative research providing information on the following:

- ◆ Cultural barriers to access within the health care system and the Black and Caribbean community
- ◆ Socio-environmental risk factors within society and health care institutions
- ◆ Health status of the Black and Caribbean community.

Multicultural health literature indicates that barriers to access can stem from differences between the cultural values and norms of a community and those of the health care system available to its members. The focus of multicultural literature is on differences in language and between eastern and western cultures.

This tends to exclude issues related to racial discrimination, linguistic and cultural differences among English- or French-speaking populations, and African culture that are relevant to immigrants from the Caribbean and Africa and Canadian-born blacks (Masi, Mensah and McLeod, 1993). The literature on multicultural health makes reference to communication issues in the Canadian health care system unrelated to language differences (Bhimari and Acorn, 1998). Accents, direct and indirect ways of communicating information, what is considered to be private information and body language affect cross-cultural communication and have

been identified as a barrier to health care access by cultural minorities.

The focus of multicultural literature is on differences in language and between eastern and western cultures. This tends to exclude issues related to racial discrimination, linguistic and cultural differences among English- or French-speaking populations, and African culture that are relevant to immigrants from the Caribbean and Africa and Canadian-born blacks.

Systemic discrimination is reflected in the composition of personnel and decision-makers and approaches and practices developed to serve a homogeneous population. In addition, the attitudes and lack of cross-cultural competencies of individual providers of care within the system have a negative impact on the quality of care

given to minority clients (Bhimari and Acorn, 1998).

Black and Caribbean Community

The multicultural literature indicates that when, why, whether or where help is sought or advice followed are influenced by beliefs (Bhayana, 1994). Literature specific to the values and behavioural norms of people from the Caribbean (Glasgow and Adaskin, 1990; Kendall, 1989) indicates that members of the Black and Caribbean community attribute illnesses to both spiritual and physical causes. As a result, many do not go to the doctor for regular check ups or minor illnesses. Hospitals are viewed as places to die and are avoided unless there is an emergency.

Clinics or health centres are viewed more positively. Cultural norms related to privacy also influence what information is disclosed to health professionals and willingness to discuss intimate

body parts or to reveal unclothed bodies for an examination.

It seems that many Caribbean and African immigrants are unfamiliar with the roles and functions of personnel in the

Hospitals are viewed as places to die and are avoided unless there is an emergency. Clinics or health centres are viewed more positively.

Canadian health care system. In addition, communicating with health care personnel is difficult because of differences in language, accent, terminology used to describe body parts and illnesses and ways of communicating. Doctors and other health care personnel seem unable to gather information from Caribbean and African clients who tend to use an indirect style of communication that is not familiar to them. Studies recommend the use of pictorial depictions in communication (York Community Services, 1999; Centre for Addiction and Mental Health Research, 1999 & 2000; and Murty, 1998).

Diet is described as central to the health of the Black and Caribbean community. Foods in the traditional Caribbean diet are described as being high in starches, fats, sugar and salt. Many foods are prepared by frying. However, there is belief in balanced nutrition consisting of meat, carbohydrates, fruits and vegetables. Studies indicate that on arrival immigrants are usually in good health that tends to deteriorate with length of residence in Canada. This is attributed mainly to changes from traditional foods to prepared foods that are high in fat (Vissandjee et al, 1999 and Bhayana, 1994).

Family structure is another aspect of culture that is seen as having an impact on the Black and Caribbean community's access to health care. In the case of Caribbean and African immigrants, the absence of the support of extended family for a family unit (single parent or two-parent) leaves it vulnerable to socio-environmental pressures and stresses.

Socio-Environmental Risk Factors

The literature indicates a high level of stress within the Black and Caribbean community. Racism, adjusting to a new society and unrealized expectations are the main sources of stress. Stress is recognized as a major factor in mental health and other illnesses and diseases (Perrin, 1998). The community also appears to be at risk from institutional factors related to the lack of representation within organizations, cultural competence of health professionals and other systemic barriers.

Societal Risk Factors

Overt, covert and systemic discrimination against Blacks has been well documented (Isaac, Barbara, 1991). In the Black and Caribbean community, coping with racial prejudice and discrimination is a major source of stress (Isaac, 1991; Kendall, 1989; Canadian Task Force on Mental Health Issues Affecting Immigrants and Refugees, 1988). Racism also affects the quality and kind of health care provided to a community (Bhimani and Acorn, 1998).

Other sources of stress in the Black and Caribbean community are the effects of immigration. These include single parent families functioning without the support of the extended family and difficulties in the parent-child relationship. Parents are also experiencing difficulties in adjusting to Canadian parenting styles and children are encountering problems in

Racism, adjusting to a new society and unrealized expectations are the main sources of stress. Stress is recognized as a major factor in mental health and other illnesses and diseases.

school (Dapaah-Opoku, 1995; Isaac, 1991). Seniors from the Caribbean are affected by aging in a different cultural context (Glasgow and Adaskin, 1990).

In addition, their wisdom and experience become irrelevant in Canadian culture and their advice is neither sought nor needed. The literature indicates that intergenerational stresses combined with the effect of migration can place the family unit to higher degree of risk in terms of physical health and mental health (Bhayana, 1954).

Seniors lack services specific to their needs and are unaware of services available to all seniors (Isaac, 1991; Ontario Ministry of Citizenship, 1991). Language, literacy and transportation are issues affecting the ability of seniors to function effectively (Multiculturalism, Aging and Seniors, 1989).

Parent-child and school difficulties experienced by teens and youth are manifested in isolation, depression and aggressive behaviour that can lead into the correction system and then the penal system (Isaac, Barbara, 1991). Single-parent responsibilities, parent-child conflicts and family violence are major sources of stress for many women in the Black and Caribbean community (Vissandjee et al, 1999; and Mathew and Carter, 1997).

Many men in the Black and Caribbean community suffer from depression and isolation due to unemployment and underemployment. Unrealized employment expectation due to employment below their education, training or experience is common to men and women in the community (Isaac, 1991; Centre for Addiction and Mental Health Research, 1999 & 2000; and York Community Services, 1999). According to the literature, many blacks work long hours in more than one job, are given unpopular shifts and experience frequent layoffs (Kendall, 1989). Studies on the effect of shift work indicate that it increases the risk of injury and can lead to digestive difficulties and heart disease (Women's College Hospital, 1998).

In addition to stress, living in poor quality public housing due to low income (see Section 1.1) is a source of frustration, despair and the lowering of tolerance levels (Isaac, 1991; Kendall, 1989). Over one-half of Somali refugees live in public or subsidized housing (Opoku-Dapaah, 1995).

In addition, the large portion of income used on private housing means less money available for nutritious food (Isaac, 1991; and Glasgow and Adaskin, 1990).

Health Care Institutions

Institutional discrimination is reflected in poor representation of blacks among health care personnel, especially at the decision-making levels. This is affecting the provision of appropriate care to the community (Morton, 1999; Doyle and Visano, 1987). Institutional discrimination is seen as being overshadowed by concern for more deliberate and blatant forms of racism.

Many health institutions seem to lack information on the cultural and racial characteristics of the population in their service area. Examples were given of Ethiopian women seeking treatment late in their pregnancy and being refused treatment by health care providers (Centre for Addiction and Mental Health 1999 & 2000) and social service counsellors and health practitioners who are unable to counsel effectively because they do not understand their clients' backgrounds.

Institutional discrimination is seen as being overshadowed by concern for more deliberate and blatant forms of racism.

Other access barriers for the Black and Caribbean community are lack of information in African languages and a shortage of professional translators. The practice is to use cleaning or clerical staff or children in the place of professional interpreters. This is considered to be inappropriate, ineffective and a barrier to access (Lee, 1994).

The community's health is also affected by the lack of funding for community organizations that serve its needs. Studies show that the ethnic community in Canada plays a significant role in developing and accessing formal and informal support networks (Doyle and Visano, 1987; and Kobayashi and Moore, 1998). The health system is seen as two-tiered consisting of well-funded mainstream organizations and ethno-specific organizations that lack adequate funding (Davis, 1990).

The literature contains recommendations to foster institutional change and to support community-based organizations.

The health system is seen as two-tiered consisting of well funded mainstream organizations and ethno-specific organizations that lack adequate funding

They include attaching explicit conditions to funding for voluntary organizations to ensure support of ethnocultural populations and ethno-specific organizations; and operational support

for organizations serving ethnocultural populations.

Health Status of the Black and Caribbean Community

The review of literature on illnesses and diseases affecting the Black and Caribbean community revealed quantitative information gaps in relation to prevalence. It also illustrated the lack of access to related health care resources.

HIV/AIDS

A recent study indicates that the majority of deaths from HIV/AIDS in the homosexual population are occurring among Caribbean-born men. An estimated 300 Caribbean-born men in Ontario are HIV infected and many more are at risk of acquiring infection because of lack of culturally targeted and appropriate interventions (Remis and Whittingham, 1999). Also at risk are African and Caribbean women as indicated by the high infection occurring in mother-infant pairs. Informal volunteer reporting indicates that 70% of

the mother-infant transmissions in recent years were among women from Africa and the Caribbean (Remis and Whittingham, 1999).

According to the literature, the rate of HIV infection is 20 times greater in the Caribbean community and 60 times greater in the African community than in the heterosexual non-injection drug using population in Ontario.

An estimated 300 Caribbean-born men in Ontario are HIV infected and many more are at risk of acquiring infection because of lack of culturally targeted and appropriate interventions. Also at risk are African and Caribbean women.

It seems that a significant percentage of infection is occurring in Canada. Mainstream approaches to prevention do not appear to be working (Simms, 1996). The religious view that HIV/AIDS is a sign of divine punishment is popularized in Caribbean music. In addition, HIV/AIDS is considered to be a gay white man's disease unlikely to affect women and "strong-looking men". These homophobic attitudes are perpetuated in popular Caribbean music.

Recommendations for action are as follows:

- ◆ Inclusion of the Caribbean and African population in the National AIDS Strategy as the Aboriginal population was prioritized in the last strategy.
- ◆ Development of guidelines for HIV testing, condom use and partner notification that are appropriate for the African and Caribbean community
- ◆ Additional studies to define the psychological, social and behavioural determinants of HIV transmission regarding infections occurring in Canada.

Sickle-cell Anemia

Sickle-cell anemia is an inherited blood condition that affects people with origins in Africa, the Mediterranean, South and Central America and Southern India (Canadian Sickle Cell Society; Serjeant, 1992; Bowman and Murray, 1990).

The Sickle Cell Association estimates that the sickle cell trait is present in 1 out of 10 Blacks and that approximately 50,000 people in the community could have it. No actual data exist on prevalence in Canada unlike the U.S. Individuals who are carriers of the sickle cell trait do not express symptoms of sickle cell anemia. Sickle cell anemia occurs when a child receives a gene from

both parents who are carriers of the sickle cell trait. An estimated one out of 400 black babies are born with sickle cell anemia. It should be noted that in contrast to the few Canadian sources of information on sickle cell anemia, the literature research revealed a variety of sources. This is reflected in the availability of screening and treatment protocols in the U.S.

Lupus

Lupus is autoimmune disorder that affects people of African origin (Women's College, 1997). It is an incurable autoimmune disorder that tricks the body into attacking its own tissue. According to the Lupus Society of Canada, 50,000 Canadians are affected by this disorder. It mainly affects women age 20 years – 40 years. There are several lupus associations in Ontario and at least one in Nova Scotia, but their focus does not seem to be on the Black and Caribbean community. Unlike the U.S. associations, the Canadian associations do not include ethnicity in their information about who is affected by lupus (<http://www.lupuscanada.org>).

Diabetes

The literature indicates that people of African descent are more likely to develop diabetes and to suffer complications such as blindness, kidney damage and amputation of lower limbs (Pride, March 2000; Pride, April 13-19, 2000; and <http://www.diabetes.ca>).

Women over 65 years seem to be particularly at risk.

The traditional Caribbean diet, high in fat, salt, sugar and starch, is considered to be the main contributor to its development and severity (Pride, April 13-19,

2000). Switching from traditional foods to prepared Canadian foods is also considered to be a contributing factor. (Simms, 1996; and <http://www.diabetes.ca>). Research by the Canadian Diabetes Association is under way to link changes in diet from immigrants' country of origin after coming to Canada (Pride, March 2000). However, there is no research specific to Caribbean foods and eating habits within the community.

People of African descent are more likely to develop diabetes and to suffer complications such as blindness, kidney damage and amputation of lower limbs.

Heart Disease and Stroke

According to the Heart and Stroke Foundation, 23,000 Canadians die every year from heart disease and stroke (<http://www.hsf.ca>). The Heart and Stroke Foundation identifies diabetes and hypertension as risk factors in the development of heart disease and strokes. Diabetes is having a great to extreme impact on the Black and Caribbean community (see Section 2.3.4). No Canadian studies were found related to hypertension in the Black and Caribbean community in Canada.

A study on heart disease and stroke in women, funded by the Heart and Stroke Foundation, identified Black and South Asian women as having a higher risk of heart disease and stroke than other women (Heart and Stroke Foundation, 1998). Nevertheless, there is no indication that ethnicity is being included in the routine collection of data on the prevalence of heart and stroke conditions. The web site of the Heart and Stroke Foundation showed a focus on information related to gender and age.

Cancer

Nothing specific was found on the prevalence of cancer in the Black and Caribbean community in Canada. U.S statistics indicate a high prevalence in its black population (Washington, 2000). Similarly, no qualitative information was found in relation to prostate cancer in black men in Canada. Only one qualitative study was found that relates to breast cancer in black women (Black Women's Health Program, 1999). This study focused on screening issues.

Preventative practices that involve screening and long-term follow-up may not be appropriate for the Black and Caribbean population (Simms, 1996). Simms suggests that current preventative strategies need to be examined and revised to take into consideration cultural norms. As stated in a study of the health of new immigrants, prevention strategies should reflect perceptions of prevention and health (Vissandje et al, 1999). Studies show that participation in breast screening programs by culturally diverse groups remain low in spite of reduction in language barriers and increased awareness of the program (Bottorff et al, 1999).

Pregnancy

The literature review did not reveal any quantitative studies on birth weight or infant mortality in relation to the Black and Caribbean Canadian community. A qualitative study by a Masters of Nursing student identified the existence of racism and culturally insensitive health care professionals in Nova Scotia hospitals (Touch Base, March 2000). As discussed in previous sections, it is estimated that one out of 400 black babies are born with sickle-cell anemia. There is also a requirement for appropriate health care in childbirth for African women with female genital mutilation (Kendall, P. R., 1992).

In addition, AIDS in the heterosexual community is resulting in the birth of babies who are already infected (see Section 2.3.1). These concerns are based on estimates and not actual quantitative studies.

Physical Disabilities

According to the literature, conditions such as diabetes and hypertension are contributing to the loss of sight and mobility by members of the Black and Caribbean community (Pride, April 13-19, 2000:14). Information was not found regarding support provided to them. Similar to other conditions affecting the Black and Caribbean community, no data were uncovered on the prevalence of disabilities.

Mental Health

The literature links mental disorder in multicultural populations in Canada to discrimination, other related sources of stress and post-traumatic disorder (Canadian Task Force on Mental Health Issues Affecting Immigrants and Refugees, 1988; and Dapaah-Opoku, 1995).

While research has yet to establish causal links between discrimination and mental disorder, it is hard to imagine that the relentless experience of rejection does not jeopardize one's mental health.

Canadian Task Force on Mental Health Issues Affecting Immigrants and Refugees, 1988

The literature indicates high levels of stress in the Black and Caribbean Canadian community and refugees in the community are experiencing a high level of depression (Lee, 1994; York Community Services, 1999; Centre for Addiction and Mental Health Research, 1999 & 2000). Relevant to the experience of members of the

Black community is the growing interest in studies related to post-traumatic disorders.

Generally, immigrants are reluctant to access mental health services because of the stigma attached, family pride and the fear of deportation. Other barriers include lack of familiarity with available services and the skills to access these services (Lee, 1994). This also applies to the Black and Caribbean community. Mental health services are underused by the community and there is an absence of cultural sensitivity in the diagnostic process. In addition, there is a lack of black mental health professionals (Isaac, 1991; Canadian Task Force on Mental Health Issues Affecting Immigrants and Refugees, 1988).

The literature indicates that members of the Black and Caribbean community tend to be diagnosed in the late stage of mental disorder and the majority of persons in care are brought in by the police. The lateness of diagnosis is attributed to beliefs about the cause of mental illness. In the Black and Caribbean community there are beliefs that fate, supernatural forces,

While research has yet to establish causal links between discrimination and mental disorder, it is hard to imagine that the relentless experience of rejection does not jeopardize one's mental health.

heredity or "too much studying" cause mental illness or "nerves". Therefore, there is a tendency to seek the help of folk healers, religious leaders or close friends for cures to mental health disorders (Glasgow and Adaskin, 1990; Canadian Task Force on Mental Health Issues Affecting Immigrants and Refugees, 1988).

Late treatment is also attributed to biased assessments. Stereotypes such as lazy, lethargic, unmotivated and aggressive that are commonly attributed to Blacks are also classic symptoms of depression. As a result Blacks with these symptoms may be assessed as behaving "normally". On the other hand, biased assessment seems to be resulting in Blacks being diagnosed more often than whites as schizophrenic (Canadian Task Force on Mental Health Issues Affecting Immigrants and Refugees, 1988).

Although the literature makes several references to the impact of racism on mental health, no comprehensive study has

Stereotypes such as lazy, lethargic, unmotivated and aggressive that are commonly attributed to Blacks are also classic symptoms of depression. As a result Blacks with these symptoms may be assessed as behaving "normally".

been done to assess the impact of racism on mental and physical health.

Consultations

Consultations for this study were carried out with 32 key informants consisting of 20 representatives of organizations and 12 knowledgeable individuals in the Black and Caribbean community in Ontario and Nova Scotia (see Appendix A). A standardized questionnaire was used to conduct face-to-face interviews with key informants. The mainly open-ended questions focused on the following:

- ◆ Influences on health-seeking behaviours
- ◆ The health status of the community
- ◆ Barriers to access to services and information
- ◆ Recommendations for future action

Health-Seeking Behaviours

Key informants identified family structure, cultural beliefs related to health and gender-specific attitudes to be significant influences on health-seeking behaviours in the Black and Caribbean community. They indicated that health care providers need to consider these when providing services or information to the community.

Family Structure

According to key informants, there are many single-parent families in the Black and Caribbean community. They attributed this situation to historic factors, migration within Canada and patterns of immigration to Canada. Key informants pointed out that many single parents lack the time to visit the doctor and have difficulty affording medication. As a result, many families rely on home remedies and only go to the doctor if seriously ill. Therefore check-up visits are rare.

Single parent families also tend to have higher levels of stress that affect children and adults in the family. In addition to the customary single parent family, in Nova

Scotia in particular, there are families that are headed by grandmothers. This is the result of migration of daughters or sons who leave their children in the care of their grandmother. Many of

You educate the female, you educate the household, you educate the male, you educate an individual.

these older adults have difficulty communicating with doctors who use terminologies they do not understand.

It was pointed out that families in the Black and Caribbean community, regardless of structure, rely on the females in the household to give information about health. As one informant said, “You educate the female, you educate the household; you educate the male, you educate an individual.” Religious leaders are also regarded as reliable sources of information about health matters.

Beliefs about Health and Illness

Most informants suggested that beliefs should be factored into diagnosis and treatment of members of the Black and Caribbean community. They indicated that in the Black and Caribbean community spiritual health and physical health are linked. These include the belief that good spiritual health leads to good physical health and that there are divine reasons for ill health. Prayers, reading the Bible or the Koran, and consulting with religious and spiritual practitioners are common reactions to illnesses. The use of family cures or herbal medicines is also common and tends to be the first reaction to signs of illness. As a result, many seek medical advice only if these other methods have been unsuccessful.

Even when there is no reliance on religion or herbal remedies, the general trend is to wait until one is sick before seeking medical attention. Key informants pointed to current research that states that very few in the community have a family physician. An example of this is pregnant women who tend to wait until late in their pregnancy to seek medical attention because pregnancy is not regarded as a condition for which one should seek medical attention. Informants also reported that health conditions and family medical histories may not be fully disclosed to health professionals. Many in the community believe that health matters are personal and private.

Gender-Specific Attitudes

According to key informants, women tend to access treatment more readily than men. However, there are cultural practices that prohibit or prevent some women from accessing health care. For example, Muslim women would not go for gynecological or breast exams when they involve male doctors or technicians. In some places in Africa, female nurses are trained to deliver these exams. Key informants suggested that female practitioners be available when necessary to carry out breast exams and pap smears.

Consultation with key informants indicated that although not restricted by religion, many Caribbean women are not comfortable exposing their bodies to health professionals. Culturally, people from the Caribbean are often shy and secretive about their bodies and body parts are not referred to by their biological names.

An example was given of a research project on screening for cervical cancer in which women in rural areas in the Caribbean were given instructions on how to do their own pap smears. This method was found to be as effective as samples done by health care professionals.

An additional factor to be considered is female circumcision or female genital mutilation (FGM), as it is referred to in Canada. Key informants had different views about its effect on women and how they view their bodies. Informants from the African countries that practice FGM do not consider it to be a problem for women. Other informants said that as a result of FGM, women are embarrassed about their bodies and do not seek health care that involves gynecological examinations.

Some of the female informants also stated that white male physicians do not take their health concerns seriously nor address their issues adequately. According to them, white male doctors stereotype black women as being strong and having a high pain threshold.

Key informants pointed out that men often do not access health care as readily as women do. As a result of male pride many males do not go for physical exams. Examination of the prostate in

Women in rural areas have been instructed to do pap smears for themselves. This method was found to be as effective as samples done by health care professionals.

particular is avoided because it is seen to be too intrusive.

Health Status of the Black and Caribbean Community

Organizations and individuals consulted for this study, indicated that the health status of the Black and Caribbean community is affected by health determinants such as racism, socio-environmental conditions and barriers to formal and institutional care. In addition, a variety of health conditions are seen to be affecting the community (see Table 1). These are discussed in the following sections.

Determinants of Health

Racism and Socio-Environment Conditions

All of the key informants stated that racism has a negative affect on determinants of health such as self-esteem, education, employment, income, housing and living standards. This is contributing to high dropout rates from schools, under-employment of immigrant professionals, unemployment, career stagnation and low incomes. Unrealized job expectations and loss of status have eroded the self-esteem of many adult males. Low incomes mean that many can not afford proper housing or healthy nutritious foods. They also indicated that living with racism is a source of stress.

Literacy was identified as a problem within the Black and Caribbean community. According to key informants, low reading levels are found in children in the school system and among older people. In Nova Scotia, before 1956, education was not available beyond grade eight and the community had to "fight the county to extend schools beyond grade eight."

Racism has a negative affect on determinants of health such as self-esteem, education, employment, income, housing and living standards.

Formal and Institutional Care

Informants also reported that members of the community do not have enough knowledge about health care resources that are available in Canada. Many are not aware of where to go and what questions to ask in order to access these services. They also indicated that many in the black community are not even aware that they are entitled to second opinions or that they can

change family physicians or even that they have the right to a medical doctor.

Informants described the system as two tiered in which who you know, what you know and your level of income determine the waiting period for access to tests and specialists. In Toronto, health cuts and the closure of hospitals that maintained ties to the community are resulting in decreased opportunities for community input into decision-making. In the opinion of study informants, where there are black persons on boards and as part of the staff of health facilities, more programs and services are made available to the black population.

Many of the respondents pointed out that low quality or no health services are often delivered to blacks, especially in the Halifax area. In Halifax, there are no hospitals in outlying areas highly populated by blacks, who also have no or limited access to public transportation to access treatment in the city. Even mobile health units, with some exceptions, do not target the black communities on the outskirts of the city. A similar situation was described in Windsor. Mobile units are clinics on four wheels operated by health professionals. They are mainly used for breast examinations and dental care.

In response to institutional barriers to quality health care, some people from the Caribbean and Africa are travelling to their country of origin to seek medical care.

Health cutbacks have led to the decision to close the only hospital on the west-side of Windsor where many from the black population reside. Furthermore, in some hospitals in Toronto, key informants said that Africans tend to be automatically screened for tuberculosis and HIV/AIDS. Many feel targeted because it is not a test automatically given to persons from other groups.

In response to institutional barriers to quality health care, some people from the Caribbean and Africa are travelling to their country of origin to seek medical care.

Chronic Conditions

Diabetes

Seventy percent of the individuals and representatives of organizations consulted for this study, indicated that diabetes is having a great to extreme impact on the Black and Caribbean community (see Table 1). According to these key informants, diabetes, which is also called "sugar" and "bad blood," is affecting mainly adult males and females in the 35 plus age category. The high impact on older people, over 50 years is seen as being due to the lack of awareness and information about diabetes and reliance on home remedies. As a result, many are receiving treatment at a late stage. "Many have died without knowing they had it" (Key Informant, East Preston, Halifax). A few informants expressed concern about the incidence of juvenile diabetes.

Table 1

Health Concerns in the Black and Caribbean Community					
Health Concern	Low %	Growing %	Moderate %	Great %	Extreme %
Diabetes	5	20	5	50	20
Heart/Stroke	4	19	29	19	29
Hypertension	9	19	19	24	48
Arthritis	10	–	10	50	30
Asthma*	29	–	–	57	14
HIV/AIDS	30	15	10	30	15
Lupus	39	22	11	11	17
Sickle Cell	35	15	10	20	20
Breast Cancer	11	17	22	11	39
Prostate Cancer	18	18	18	28	18
Alcohol Addiction	–	19	13	31	37
Drug Addiction	22	11	5	28	33
Smoking	–	25	25	19	31
Depression	–	–	35	25	40
Schizophrenia**	–	–	25	38	38
Physical Disabilities	29	6	35	12	18
Learning Disabilities	25	–	12	19	44
Pregnancy	29	7	14	21	29

Totals may not add up to 100% due to rounding.

* Other chronic conditions mentioned by respondents were sexually transmitted diseases (growing), hepatitis (moderate).

** Other mental health conditions mentioned by respondents were stress and low self-esteem. These were rated from moderate to extreme.

Source: Canadian Centre on Minority Affairs Inc, 2000: Community Informant Consultations

Treatment that relies on following the Canadian Food Guide is seen as being culturally inappropriate. According to key informants, many people have difficulty keeping to a diet they do not understand or find appealing. Another difficulty indicated by key informants, is the requirement to prepare foods based on recipes and exact measurements of ingredients. This can be a problem since Caribbean and African foods are usually prepared without the use of recipes. In response, key informants have suggested the following:

- ◆ Research on dietary practices in the Black and Caribbean community
- ◆ Research on the nutritional value of Caribbean and African foods
- ◆ Program to show the kinds of Caribbean and African foods that contribute to good health
- ◆ Changes to the Canadian Food Guide

Treatment that relies on following the Canadian Food Guide is seen as being culturally inappropriate.

Heart Disease and Stroke

Less than 50% of informants judged heart and stroke as having great to extreme impact on the Black and Caribbean Canadian community (see Table 1). However, almost 20% indicated that it is of growing concern. It is seen as affecting men and women between 30 years and 50 years of age.

This condition is attributed to diets in the community that are described as having “lots of grease and salt,” “oils and fats” and “lots of fatty foods.” Key informants also pointed to the way foods are cooked involving a great deal of frying with lard and other cooking oils as a causal factor. They also associated heart and stroke condition with the following:

- ◆ Hypertension, a condition that is prevalent in the community
- ◆ Stress from dealing with racism

Informants also felt that there is a lack of knowledge and awareness about heart disease in the community. It was felt that “blacks are not being targeted, only the white middle class” in the dissemination of information on awareness and prevention of heart disease.

- ◆ Stress from working at more than one job to support family and lifestyle
- ◆ Poverty
- ◆ Lack of exercise
- ◆ Hereditary and genetic factors.

Informants also felt that there is a lack of knowledge and awareness about heart disease in the community. It was felt that “blacks are not being targeted, only the white middle class” in the dissemination of information on awareness and prevention of heart disease.

According to informants, Black and Caribbean patients are prime candidates for extreme treatments such as triple bypass. In addition, many medications given to Blacks for their condition may have side effects.

Hypertension

Hypertension was reported by 72% of the key informants as having a great to extreme impact on the Black and Caribbean community. It was felt that although people in the community are aware of hypertension or “pressure”, it is not taken seriously. People do not seem to know that it “can lead to kidney failure” and “its direct link to heart and stroke conditions.” This lack of awareness was attributed to people being “given pills without other information.”

According to informants, hypertension is the result of stress that comes from “being black in Canada,” dealing with stereotyping and adapting to a new country and culture. Unemployment and poverty especially in Nova Scotia are also sources of stress.

It was felt that many people are not seeking treatment for stress “because people in institutions do not look like us.”

At least half of the households are experiencing stress. Kids are on Ritalin and mothers on Prozac.
Key Informant, East Preston, Halifax

It was felt that many people are not seeking treatment for stress “because people in institutions do not look like us.”

Diets that include salty foods (e.g. preserved meats and fish), prepared foods and junk food are also seen as a contributing factor in the prevalence of hypertension within the community. In the opinion of key informants, there is a need

for “more education about diet and reading food labels from an early age that is targeted to men and women.” Weight control and lack of exercise, especially by men, were identified by informants as contributing to hypertension in the community. It is also seen as a condition that “runs in families.”

Treatment mainly consists of pills. However, according to informants, hypertension in black women cannot be controlled by current prescription drugs. Many drug trials are based on European populations and they do not include black population groups. Informants recommended regular check ups that include getting kidney function checked.

There is a need for more education about diet and reading food labels from an early age that is targeted to men and women.

Other Chronic Conditions

Arthritis, asthma, hepatitis and sexually transmitted diseases were identified as having a noticeable effect on the Black and Caribbean community. Eighty percent of the informants who identified arthritis felt it is having a great to extreme impact (see Table 1). Osteoarthritis in young women and seniors was mentioned most frequently. It was attributed to the absence of milk and cheese in diets. According to informants, lactose intolerance is common among Somalis and soya is not an alternative source in that community. As well, lactase pills that would allow the consumption of dairy products are considered to be too expensive. An additional factor identified by key informants is the tendency for blacks to have scoliosis, curvature of the spine. Aging and accompanying hormonal changes in women were also mentioned. It was felt that blacks are not seen as part of the at-risk group regarding osteoporosis because they do not fit the usual profile in current use: fair skin, small boned with a sedentary life style.

Paget’s disease, that results in difficulties in walking due to the swelling of joints and deterioration of the bone, was identified as being common in black people. According to informants, doctors have indicated that because this condition is not affecting the majority population, there is no treatment for it.

Blacks are not seen as part of the at-risk group regarding to osteoporosis because they do not fit the profile in current use: fair skin, small boned with a sedentary life style.

Asthma was also identified as having a great to extreme impact on the community (see Table 1). According to informants, in East Preston, Halifax, it is affecting 1 in 10 children in a day care centre. Young and older people are also being affected and related deaths are occurring. In East Preston, there is a clinic every four months for people with asthma.

Poor indoor air quality and environmental pollutants are seen as contributing to its presence in the community. It was reported that a study on asthma and blacks in Nova Scotia is being conducted by a research team that does not include anyone from the Black community.

Hepatitis B and C are regarded as having a moderate impact on the community, especially on Somalis and other newcomers. According to key informants, members of the Black and Caribbean community are also being affected by the following: sexually transmitted diseases such as gonorrhoea especially among newcomers to Canada and college and university students; glaucoma; anemia in women due to the presence of fibroids; tuberculosis especially among newcomers; multiple sclerosis; sarcoidosis; leukemia especially among young people; and varicose veins.

The effects of female circumcision are also of concern and it was felt that the community should be allowed to address this issue in a way that is comfortable.

HIV/AIDS

Less than 50% of key informants rated HIV/AIDS as having great to extreme impact on the Black and Caribbean community (see Table 1). Key informants’ assessment of the impact of HIV/AIDS varies by region. Informants in Nova Scotia tend to give it a low impact with many indicating that they know of only one person or no one who is affected. One Nova Scotia informant indicated that AIDS “is very high and seems to be increasing although people don’t talk about it and it is being ignored by the community.” Key informants in Ontario tend to see it as being more prevalent.

Community is aware of AIDS and HIV but they don’t believe it’s a problem. They lack the education and sexuality is not a topic that is openly discussed
Key Informant, Toronto

According to key informants there is a great deal of fear surrounding HIV/AIDS. They recounted stories of people with AIDS and HIV being abandoned by the community. Key informants described AIDS as being a taboo subject in the community.

Key informants in Ontario felt that except for the Black Coalition for AIDS Prevention, "little is being done to provide the Black and Caribbean community with information and education about AIDS and HIV."

Key informants reported that a recent study in Toronto suggests that black homosexual males are the third highest group affected with AIDS. There are also indications from numbers collected by a hospital in Toronto that a high percentage of babies born with AIDS are being born to black women. This is seen as evidence of heterosexual transmittal in the community. Key informants reported concern about the lack of testing of pregnant women in spite of the 1998 Ontario policy that requires doctors to test pregnant women for HIV/AIDS. Less than 50% of women are being tested because doctors don't have the time to provide the counselling that is part of the testing process.

Key informants in Ontario felt that except for the Black Coalition for AIDS Prevention, "little is being done to provide the Black and Caribbean community with information and education about AIDS and HIV." Key informants in Hamilton reported that the AIDS Network's gay focus makes black women uncomfortable, so they do not go there. They also indicated that there is limited assistance for obtaining expensive medication and there is no money for prevention.

Sickle-cell Anemia and Lupus

Key informants identified both sickle cell anemia and lupus as having an impact on the Black and Caribbean community. In general, informants tended to be more familiar with sickle cell anemia and 40% rated it as having a great to extreme impact on the community (see Table 1). Key informants in Nova Scotia were more likely to see it as having less of an impact than those in Ontario. According to them, there is no testing for the trait in Nova Scotia and people are only tested if they ask for it. In addition, they felt that the doctors in Nova Scotia do not know how to treat sickle cell anemia.

There is a push in Nova Scotia for testing, especially of pregnant women. There is no research, no service and no diagnosis.

There is a push in Nova Scotia for testing, especially of pregnant women. There is no research, no service and no diagnosis. Key Informant, East Preston, Halifax

According to informants in Ontario, testing for sickle-cell is available. Pregnant women are being tested but many people have not been tested. It was noted by a health professional that many children in Ontario are affected. In Windsor, no treatment is available and sickle-cell patients are sent to Detroit. This practice was questioned by informants in Windsor.

Blacks are disregarded. Why do we have to fight when we pay taxes? We should get care.

Key Informant, Windsor

Lupus was called the "unknown killer" that affects young black women. One respondent alone knew of four recent cases. In the opinion of informants, lupus is usually misdiagnosed.

It was also felt that not enough research is being done to document the effects of lupus on young black women.

I know people who were not diagnosed. We don't hear about this (lupus) and doctors don't tell us.

Key Informant, Halifax

Cancer

Breast Cancer

Half of the key informants consulted for this study rated breast cancer as having a great to extreme impact on the Black and Caribbean community (see Table 1). According to key informants, there is a high incidence of breast cancer among black women. Smoking and stress were identified as contributing to the incidence of breast cancer in black women.

In Nova Scotia, screening is available through a mobile unit. It provides service to the Black community in the Halifax area through a women's clinic in East Preston.

Although screening through this clinic has been "well received", many "black women don't go for testing because they don't want to be physically touched." Modesty does not allow them to expose their breasts to strangers.

There is a high incidence of breast cancer among black women.

Both young and older women are affected and many are dying according to key informants. They felt that the 50 years and over rule for screening does not apply to black women. In the opinion of some key informants, breast cancer “does not show up in black women until it is serious because they only find a lump when it is huge.” Therefore, they question the use of lumps as an early indicator. When it comes to treatment, key informants were critical of the treatment black women are receiving from white doctors. According to them, everything is a struggle and there is a lack of referrals to specialists. One informant expressed the situation in the following way:

Black women find it hard to advocate for themselves in a system they don't understand and does not understand them. Eventually they back away from the system.

Key Informant, Hamilton

Specific reference was made to black physiology not being understood in regard to radiation treatment and the tendency for black women to grow large tumours. It was felt that science does not understand how this affects black women. They indicated the need for a study on breast cancer and cervical cancer in black women. Also recommended were education and information to facilitate early detection and support groups for persons affected.

Prostate Cancer

Forty-six percent of key informants assessed prostate cancer as having a great to extreme impact on the Black and Caribbean community (see Table 1). Many key informants know several people who either have prostate cancer or have died from the disease. They indicated that stereotyping about black men's virility, ego, pride and a generally macho attitude are preventing black men from going for prostate examinations. Some felt that there is a lack of investigation about the effect of prostate cancer on black men.

It was recommended that from ages 18 and 20 men should be having prostate examinations rather than waiting until they are sick.

There is a lack of investigation about the effect of prostate cancer on black men.

Right now the “onus is on the person to take the initiative to get tested since it is not part of routine exams.”

Another recommendation is the need to get information to black men and encourage them to be tested for prostate cancer. According to some informants, there is a new test available that does not involve a rectal examination.

In Nova Scotia, the African Men's Health Group in Halifax, formed to educate black men about prostate cancer, has received a grant from the Canadian Cancer Society to do community outreach about prostate cancer. The Lion's Club in East Preston has brought in speakers to provide information about the disease.

Addictions

Alcohol Addiction

Alcohol addiction was given a great to extreme impact rating by 68 percent of the key informants consulted for the study (see Table 1).

I visited the treatment centre in Windsor. Black men and women are among the highest group affected with the disease. Key Informant, Toronto

According to informants, the consumption of alcohol is accepted in the Black and Caribbean community. It is seen as a way of socializing with friends and excessive drinking is not recognized as a disease. Key informants indicated that “excessive drinking” is being done by teenagers and adults. Even in the Somali community where Islamic religion prohibits it, people are drinking openly according to key informants. There are closet alcoholics in the Black and Caribbean community, mainly among males over 50 years. It is attributed to frustration “because they are highly educated and suffer from unemployment or underemployment.” Alcohol is used as a coping mechanism. It is also seen as a “hidden disease” among black women. Key informants referred to the impact on family life that is going unrecognized.

Drug Addiction

Drug addiction was given a great to extreme rating by 61% of key informants (see Table 1). It includes the use of marijuana, hash, crack, cocaine and prescription drugs. In addition, the chewing of "Khat" or "miraa," tobacco-like leaves, by Somalis was referred to by many informants.

Key informants indicated the need to get information out about the harmful effects of drug use including the chewing of khat.

According to informants, marijuana is being used by young people in schools and universities. "People are smoking everyday. They see marijuana as a herb that is good for your body." Young adults (18-35 years of age) and the middle-aged in the community were identified as users of crack and cocaine. These include women 20 years - 50 years whose addiction is hidden. Key informants indicated the need to get information out about the harmful effects of drug use including the chewing of khat.

Smoking

Half of the key informants indicated that smoking is having a great to extreme impact on the Black and Caribbean community (see Table 1). It is affecting young people as young as 12 years, older people, men and women including pregnant women. According to informants, smoking is socially acceptable and not viewed as a serious health problem that can lead to lung disease or cancer. It is also used to relieve stress.

Mental Health

Depression was assessed as having a great to extreme impact by 65% of key informants (see Table 1). It is mainly affecting men and women 22 years – 55 years. Isolated seniors are also being affected. It is attributed to lack of job opportunities, problems with the school system, parenting problems, culture shock and unrealized expectations. Key informants pointed to studies of the Ethiopian and Somali communities that identified unrealized expectations and the loss of status as factors leading to high incidence of mental health diseases among the males in these two populations. Coping with racism in Canada and the after effects of war or torture were also identified as major contributors to depression in the Black and Caribbean community.

According to key informants, depression is not seen as 'a black thing' and the word depression is not used widely in the community. Many people are not diagnosed or diagnosis occurs at a late stage. Therefore, "they may end up at a mental institution or in emergency." Mentally ill blacks also tend to end up in the criminal system and not in treatment. Another impact that was identified is the "high suicide rates among Ethiopian, Eritrean and Somali males."

Many people are not diagnosed or diagnosis occurs at a late stage. Therefore, "they may end up at a mental institution or emergency." Mentally ill blacks also tend to end up in the criminal system and not in treatment.

Schizophrenia was also identified as a mental condition that is affecting the Black and Caribbean community (see Table 1). The lack of black psychiatric professionals was noted by key informants. Medication was identified as giving black males bad side effects. The Centre for Addiction in the City of Toronto is currently conducting research on mental health in the Ethiopian community. However, key informants noted that there is an absence of black research staff at the institute.

Disabilities

Physical disabilities were seen as having a low to moderate impact on the Black and Caribbean community (see Table 1). Seniors in the community appear to be the most affected by physical disabilities due to loss of sight or hearing as a result of aging or complications from diabetes. Disabilities are also resulting from on-the-job injuries and automobile accidents.

According to key informants, many people in the community with disabilities cannot afford wheelchairs and other aides. Families with children with disabilities may send them back to their country of origin because of difficulties caring for them in Canada. It was observed that community-based organizations such as Women's Health in Women's Hands in Toronto are targeting persons with physical disabilities. However, the resources of national voluntary organizations are not being accessed by the community.

Sixty-three percent of the key informants assessed the impact of learning disabilities on the Black and Caribbean community as being great to extreme (see Table 1). Concerns were expressed about the labelling of black children as learning disabled.

The resources of national voluntary organizations are not being accessed by the community.

They felt that much of this is due to racism and cultural misinterpretation of behaviour. In other cases learning disabilities are not detected because of assumptions about the capabilities of black children. They also felt that in cases where learning disabilities such as dyslexia or ADD exist, parents are not provided with information or support.

Pregnancy

Half of the key informants rated the impact of childbirth issues on the Black and Caribbean community as great to extreme (see Table 1). According to key informants in Ontario, many women in the community tend not to take prenatal or postnatal care seriously, especially if it is not the first child. In addition, it was felt that childbirth classes are not culturally sensitive. Informants indicated problems with low birth weight and maternal death from toxemia.

Key informants indicated that due to cultural insensitivity, black women are having negative childbirth experiences. Specific reference was made about health professionals disregarding feelings of pain by black women when performing routine procedures during the birthing process. Some examples are attaching IVs and stitching tears. Informants attribute this lack of sensitivity to beliefs by health professionals that black skin is “tough” and African women can give birth without experiencing pain and know the birthing process intuitively. As a result, the delivery process is often not explained to them and they are not given the opportunity to ask questions about postnatal care.

Half of the key informants rated the impact of childbirth issues on the Black and Caribbean community as great to extreme.

Concern was expressed for the appropriate approach to childbirth for African women who have been circumcised or have experienced Female Genital Mutilation (FGM). Key informants estimate that 90% of Somali, Ethiopian and Sudanese women have experienced FGM. Health professionals in Canada are inexperienced in providing health care to FGM women. There is concern about the high level of Cesarean sections being given to FGM women who have previously given birth naturally in their countries of origin. Women’s Health in Women’s Hands, a community-based organization, has developed a pamphlet designed to educate health professionals about how to provide care to FGM women who are pregnant.

Access Issues

Consultations with key informants revealed that many health institutions and organizations are failing to provide culturally sensitive and appropriate care to the Black and Caribbean community. Key informants described the black population as being the most underserved group in the health care system.

Hospitals

Most of the key informants reported that in general, little is being done by hospitals in Ontario or Nova Scotia to reach out into the Black and Caribbean community.

According to key informants, most hospitals only provide sensitive and appropriate services when demanded by patients and/or their relatives. Key informants were critical of the practice of using children for language interpretation.

Hospitals with community advisory boards and staff from various ethnic groups were rated as being more culturally sensitive. Some hospitals have now expanded their policy to allow visits by extended family members. However, there are still problems with the lack of understanding of black cultures.

Health Centres

According to key informants in Halifax, only one health centre provides culturally sensitive and appropriate care to blacks. In the City of Windsor, informants reported that they are no services specifically targeted to blacks in the area, although there are services for low-income families and teens provided by the health centre in the area of the city where there is a concentration of blacks. In Toronto, several health centres provide culturally sensitive care. Key informants noted that such services were provided either because board members and/or staff of these organizations are black.

It was noted that the Aboriginal community, which has a health profile that is similar to the Black and Caribbean community, received funding to establish health centres in urban areas to meet its needs.

It was noted that the Aboriginal community, which has a health profile that is similar to the Black and Caribbean community, received funding to establish health centres in urban areas to meet its needs. Funding covers the cost of establishing and operating the health centres.

Voluntary Organizations

According to key informants, a few national voluntary organizations are reaching out to the Black and Caribbean community. For example, the Canadian Cancer Society in Nova Scotia has translated some of its literature into the Ethiopian language and has created brochures that are representative of a diversity of groups. The African Men's Support Group, in Halifax, has received funding from the Canadian Cancer Society to conduct outreach into the black community on prostate cancer. Informants also mentioned that some work is also being done by the Canadian Hearing Society and the United Way.

Several community-based voluntary organizations in Nova Scotia and Ontario were identified by key informants to be active in the Black and Caribbean community. With limited funding, they host conferences on access to health care, outreach to the community, advocate for the accreditation of foreign-trained health professionals, conduct research on specific conditions, and provide support groups and clinics on health matters.

Future Action

Key informants suggested that action be taken by health care providers to make their services more accessible. They pointed to the need for research to provide policy makers and decision-makers with accurate data. Suggestions were made regarding the education and training of health professionals about the Black and Caribbean community, as well as public awareness initiatives to provide information to the community. Recommendations were also made about the kinds of policies, training and capacity building required to build a foundation for a healthy community.

Access Issues

Access to health care services was identified by key informants to be a need that requires action.

They can't keep delivering the same programs when the population is changing. Key Informant, Toronto

Access to health care services was identified by key informants to be a need that requires action by health care providers. Suggested action includes the following:

- ◆ Increasing the representation of staff by hiring more Black and Caribbean health care professionals
- ◆ Allowing doctors from Africa and the Caribbean who upgrade their skills to practise in Canada instead of moving to the United States where they are allowed to practise.
- ◆ Get to know the Black and Caribbean community in their catchment area
- ◆ Comprehensive outreach using existing institutions, such as places of worship, where members of the community congregate
- ◆ Provide treatment and services to members of the Black and Caribbean community that recognize their needs
- ◆ Locate health services in areas where Black and Caribbean people live and work

Key informants identified the following service requirements by young people and adults in the community.

- ◆ Teenagers and youth in the community require access to birth control, hygiene and mentoring services. The young women in this

category may also need abortion and childcare services.

- ◆ Adults, both men and women, were seen to require mental health services and counselling in family violence. Adult men would also require counselling in relationships and family values. Specific service needs of adult women include breast screening, lupus treatment and counselling for post-partum depression.
- ◆ Long-term care institutions and services are specifically recommended for seniors in this community.

Research

According to key informants consulted for this study, there is a need for a comprehensive approach to research on the health status of the Black and Caribbean community in Canada. The research should involve:

- ◆ Data gathering to show need in terms of facts and statistics about diseases and health conditions.
- ◆ Identification of what services are lacking and why.
- ◆ Examination of the effect of racism on health within the Black and Caribbean community.

They emphasized the need for adequate funding and the use of black researchers to carry out the research. At the moment “funds are going to white groups to do research on blacks.” (Key Informants, Halifax). An exception is a small grant to the Congress of Black Women to survey households in Halifax on health issues.

There is a need for a comprehensive approach to research on the health status of the Black and Caribbean community in Canada.

Education

Throughout the consultations, key informants pointed to the need to educate and sensitize health care providers and to provide information to the community. Key informants suggested that the process should begin with health care students.

This would involve workshops for students about Black and Caribbean culture and social environment. Staff working in health care organizations should also receive cultural sensitization.

Health Care Organizations

Key informants pointed to the need for health care organizations to know the Black and Caribbean community in terms of its demographics, culture and health needs. They suggested that research be carried out to provide accurate information on the Black and Caribbean community in Canada.

Demographic information should include the following:

- ◆ Population data
- ◆ Employment, unemployment and underemployment
- ◆ Living standards
- ◆ Achievements and successes

Information on the culture of the community should include the following:

- ◆ Values
- ◆ Lifestyle
- ◆ Myths, beliefs and taboos
- ◆ Terminology in relation to disease and illness
- ◆ Ways of interpreting illness
- ◆ Eating habits
- ◆ Nutritional value of foods in traditional diets

According to key informants, health information that is provided to health care organizations about the community should include the following:

- ◆ Health issues specific to the community
- ◆ Information on health conditions that are specific to the community, e.g. sickle cell anemia
- ◆ Information on general health conditions that are having a significant impact on the community, e.g. diabetes, hypertension
- ◆ Physiological differences in response to medication and other treatment such as radiation
- ◆ What prevents people in the community from accessing health care services

They also suggested that an Advisory Committee be formed to advise Health Canada on what is needed when building and implementing programs for the Black and Caribbean community.

Community Outreach

Key informants suggested that health care providers should provide education and information to the Black and Caribbean community by doing the following:

- ◆ Translating brochures and other material into other languages
- ◆ Initiating programs to educate the Black and Caribbean community about health matters. It was suggested that people from the community affected with particular conditions be trained to provide information to the community. A similar approach is being used by the AIDS Bureau.
- ◆ Organizing monthly workshops or information sessions for the community and advertising them in community media
- ◆ Providing health education in schools
- ◆ Facilitating the formation of support groups in which people can feel free to have open discussions about health with members of their community

Key informants also suggested that specific information should be provided to young people and adults in the community on:

- ◆ Nutrition and healthy lifestyle choices
- ◆ Holistic approaches to medicine
- ◆ Health insurance for prescription medication
- ◆ Walk-in clinics for physical check ups
- ◆ Sterility due to abortion
- ◆ Simplified medical information

In addition, it was suggested that women be provided with information on coping with chronic diseases and the effects of female genital mutilation or circumcision.

Policy

In the policy area, key informants advocated for:

- ◆ A directive from Health Canada to health care organizations that receive funding from it to make the changes necessary to eliminate systemic barriers and integrate Black and Caribbean needs into the services they provide

A funding structure that recognizes and acknowledges the needs of the Black and Caribbean community.

health in the Black and Caribbean community

- ◆ A funding structure that recognizes and acknowledges the needs of the Black and Caribbean community
- ◆ A comprehensive action plan to address

Building Capacity

National Strategy

Key informants consulted for this study indicated the need for a national strategy based on health priorities identified within the Black and Caribbean community. In their opinion, the national strategy should take into consideration what has been done and what is needed to build capacity in Black and Caribbean organizations that are already serving the community.

According to them, the creation of a health strategy that incorporates the health needs of the Black and Caribbean community would require long-term commitment from Health Canada as well as community involvement in decision-making.

A national strategy based on health priorities identified within the Black and Caribbean community.

Health Management Centre

Key informants recommended the creation of a centre to:

- ◆ Carry out and share research related to health care for the Black and Caribbean community
- ◆ Gather and distribute information from community sources across Canada
- ◆ Create and maintain an inventory of Black and Caribbean health care professionals to facilitate access to their expertise
- ◆ Design and coordinate health education within the Black and Caribbean community
- ◆ Develop partnerships with health care organizations and governments
- ◆ Design culturally sensitive training for health care providers
- ◆ Be an advocate on Black and Caribbean health issues.

Community Empowerment

Raising awareness and education about health matters in the Black and Caribbean community was recommended by key informants. They pointed to the need for people in the community to take ownership and responsibility for their own health. The following approaches to health education were suggested by key informants:

- ◆ Use people with a wide sphere of influence to disseminate information in the community, e.g. religious leaders
- ◆ Use locations where people gather to distribute information and educate

- ◆ Train people affected by specific conditions to outreach into the community

They also suggested that efforts be made to encourage members of the community to consider health care careers. Specific suggestions included efforts to increase

enrollment in medical schools and the use of Black and Caribbean role models as examples of what is possible.

Raising awareness and education about health matters in the Black and Caribbean community was recommended by key informants.

Conclusions and Recommendations

The review of literature and consultations with key informants in the Black and Caribbean community identified many service and information gaps that impact on the community's health. This study also shows that the community is at risk from both community-specific and general health conditions. In addition, there are gaps in access to health care services, the provision of information, inclusion in health research and the carrying out of community-specific research.

Study recommendations focus on strategic solutions that build on resources within the Black and Caribbean community. They also address the requirement for funding to support the development of effective, responsive and well-coordinated programs and projects.

Conclusions

Health Determinants

Study findings indicate that stress is a major source of health risk in the Black and Caribbean community in Canada. Systemic, overt and covert racism and discrimination are main sources of stress. In addition, difficulties in the school system coupled with parent-child conflicts are sources of stress for parents and children. Underemployment in terms of education and experience is creating stress for the adult men and women who are affected. Seniors, who must cope with the change in their status as head of the household, often find themselves isolated. All of these add to stress levels. Stress is recognized as a major factor in mental health and other illnesses and diseases.

Statistics Canada data (Section 1.1) clearly show the disadvantaged position of members of the Black and Caribbean community compared with other racial minority communities and the general Canadian population. Health in the community is especially affected by the large number of single parent families that are functioning without extended family support. This situation developed mainly as a result of immigration patterns from the Caribbean and Africa. Both the literature review and key informants address this issue and its impact on health and access to health care.

The health care effects of economic disadvantage within the Black and Caribbean community are

compounded by systemic discrimination in health care institutions and health care services that fail to recognize its unique cultural and physical characteristics. The focus on language within multicultural health care also tends to exclude the needs of the Black and Caribbean community from consideration.

Unfamiliarity with the Canadian health care system means that members of the community are not using the system in the most effective way. The community's reliance on home remedies and reluctance to seek medical care unless seriously ill are also factors in the underuse of the health care system.

The influence of spiritual beliefs on approaches to prevention and treatment identified in the literature review and community consultations indicate the need to factor them in the development of health care projects. Health education is needed to correct erroneous beliefs about the causation of diseases.

Community-based organizations have been developed to respond to the needs within the Black and Canadian Caribbean community. Their effectiveness is hampered by inadequate funding and other resources that do not allow them to develop the necessary infrastructure to serve the community more effectively.

Health Status

Key informants and the literature identified the community's major health risks to be diabetes, hypertension, arthritis, learning disabilities, depression and related mental illness, alcohol and drug addiction, heart disease and cancer. In the case of HIV/AIDS, the literature indicated the development of a major crisis in the Black and Caribbean community, but less than 50% of key informants considered that it is having a great to extreme impact on the community. Mental health presents a particular challenge due to its link to racism, discrimination and lack of opportunities. In addition, the literature and consultations indicate bias in diagnosis and inappropriate treatment. Depression appears to be widespread and is affecting all ages and both genders. Disabilities tend to be associated with the effects of diabetes

on sight and mobility. There is a lack of comprehensive information about the prevalence of these conditions in the Black and Caribbean community. Stress is seen as a common contributing factor in all cases. Diet appears to be a major factor in diabetes, hypertension and arthritis. The need for information about prevention and treatment related to all conditions was identified.

The community is also vulnerable to disorders that affect people of African origin. These include sickle cell anemia and lupus. However, protocols for screening and treatment are not consistently used by health professionals.

Access and Outreach

The multicultural health literature contains many references to the lack of access to health care by many ethnic communities. However, consultations with key informants provided specific information related to access by members of the Black and Caribbean community. According to key informants, the Black and Caribbean community is the most underserved group in the health care system. Hospitals, with some exceptions, were seen to be doing the least to accommodate the service and information needs of the community. Health centres, especially in Toronto, appear to be more accommodating. Voluntary organizations are just beginning to reach out to the community.

Systemic discrimination is a major impediment to access and outreach. In health care organizations, it is reflected in practices that do not take Black and Caribbean cultural or physical characteristics into account, exclude members of the community from decision-making positions and give low priority to community-specific health conditions. It is also manifested in drug trials and research that exclude substantive samples from the Black and Caribbean population.

In the consultations, key informants indicated the need within the community for health information and awareness building in relation to diet, the health care system, chronic diseases, cancer, childbirth, HIV/AIDS, addiction and mental health. Service needs include screening for the sickle cell trait and services for seniors.

The literature and consultations pointed to the need for education and training of health professionals about the Black and Caribbean population, its culture, physical characteristics and community-specific conditions.

Policy and Capacity Building

Based on consultations with individuals and representatives of organizations, there appears to be a policy gap in relation to the health care needs of the Black and Caribbean community. Policies are needed to eliminate systemic discrimination and address the health care needs of the community. A national strategy that reflects the health priorities of the Black and Caribbean community is required. Also required is a vehicle to carry out the strategy. The development of a vehicle would involve building the capacity of a community-based organization to partner with health care organizations and reach out to the community.

Future Action

This study identified a wide variety of health issues within the Black and Caribbean community. Suggested actions to address them include the following:

- ◆ Qualitative and quantitative research on the demographics of the population and socio-environmental factors, health conditions within the community and program and service needs
- ◆ Establishment of collaborative networks and creation of a skills inventory and database of research information specific to the community
- ◆ Provision of information on culture, beliefs and values to health professionals about the Black and Caribbean population they serve
- ◆ Increasing representation of blacks in the health sector
- ◆ Conducting culturally appropriate outreach to educate and raise awareness about prevention and treatment of health conditions
- ◆ Inclusion of community members in the policy decision making process
- ◆ Building capacity through community empowerment and institutional supports

Recommendations

The following recommendations are based on findings from the literature review and consultation with key informants from the Black and Caribbean community:

Policy Development

1. Participation of the Black and Caribbean community in the health care policy development process:
 - a) This could involve identifying and defining policy issues, reviewing existing policies and policy evaluation
 - b) A consultative mechanism to facilitate this process

Capacity Building

1. Capacity building within Black and Caribbean organizations to enhance their ability to be effective and coordinated in helping to meet the needs of the community. Strengthened organizations would be in a better position to collaborate on initiatives to improve the health of the community. This would contribute to the sustainability of health care initiatives and require:
 - a) Assistance to community sector to build effective and long-term relationships with other health care organizations
 - b) Assistance in building the organizational and institutional capacity of organizations that can advocate on behalf of the community and facilitate the dissemination of health-related information
 - c) Assistance in the development of the community's capacity to:
 - Carry out and share research
 - Gather and distribute information to individuals and families
 - Facilitate access to expertise within the community by creating and maintaining an inventory of Black and Caribbean health care professionals
 - Design and coordinate health education for the community
 - Design culturally sensitive training for health care professionals
 - Advocate on Black and Caribbean health issues
 - d) Encouraging health-related voluntary organizations to enter into partnerships with organizations in the Black and Caribbean community

Project Development

1. Provision of support and resources to assist organizations to undertake local projects that are consistent with the health priorities of the Black and Caribbean community.
 - a) Projects that include methods and mechanisms to provide quantitative and qualitative information on health and related conditions within the Black and Caribbean community
 - b) Projects that address the delivery of health services to the Black and Caribbean community
 - c) Projects that outreach to the Black and Caribbean community to provide health education and raise awareness about prevention, treatment and accessing the health care system
 - d) Projects that enhance health professionals' knowledge of Black and Caribbean health beliefs, black physical characteristics and protocols for the treatment of conditions that are specific to the community
 - e) Projects that raise awareness within the schools about health conditions that can affect the learning ability of children in the Black and Caribbean community, e.g. sickle cell anemia and the effect of oxygen depletion on memory
 - f) Projects that address emerging health issues such as HIV/AIDS, asthma, heart and stroke disease and sexually transmitted diseases in ways that include members of the Black and Caribbean community
 - g) Projects that increase collaboration and relationship building to carry out research, develop culturally sensitive approaches to prevention and treatment and enhance access to available resources
 - h) Projects that identify and develop best practices in the areas of culturally appropriate nutrition, nutritional value of Caribbean and African foods, diets for the Black and Caribbean population and revisions to the *Canada Food Guide* that reflect cultural diversity in Canada

- i) Projects related to screening and prevention practices for breast and cervical cancer considering the ineffectiveness of current practices
- j) Projects to develop appropriate screening and treatments for other physical and mental health conditions in the Black and Caribbean community
- k) Projects that enhance the relationship between the community and mainstream health organizations to facilitate community involvement in decision-making

Advocacy

- 1. Funding of an organization to enhance its organizational capacity to advocate on behalf of the community by:
 - a) Representing community interests and views
 - b) Providing a national forum
 - c) Connecting with other stakeholders and communities across Canada
 - d) Mobilizing participation and action on health within the Black and Caribbean community

Bibliography

Black and Caribbean Canadian Health Promotion and Population Outreach Project

This bibliography presents materials on health issues related to the Black and Caribbean Canadian community. It contains Canadian sources from 1990 to 2000, as well as relevant sources from the late 1980s. Topics covered include multicultural health as it relates to Black and Caribbean health issues, Black and Caribbean cultural beliefs and values, societal risk factors and health conditions within the community.

Multicultural Health

The publications in this section address issues of multicultural health that are relevant to the Black and Caribbean community.

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Black and Caribbean Cultural Beliefs and Values

The publications in this section provide information on health-related beliefs and values of the Black and Caribbean population. They provide valuable insights into how family values, traditional eating habits, beliefs about the origin, prevention and treatment of illnesses as well as birth and death could affect access to the Canadian health care system.

- Dapaah-Opoku, Edward. 1993. Adaptation of Ghanaian refugees in Toronto. Doctoral Research Fellow, Centre for Refugee Studies, York University. Toronto: York Lanes Press.
- Dapaah-Opoku, Edward. 1995. Somali refugees in Toronto: A profile. Doctoral Research Fellow, Centre for Refugee Studies, York University. Toronto: York Lanes Press.
- Glasgow, J. H., and Adaskin, E. 1990. The West Indians. In *Cross-cultural caring: A Handbook for Health Professionals in Western Canada*. Morrison, Nancy Walker, and Richardson, Elizabeth, eds. Vancouver: University of British Columbia Press.

Kendall, P.R.W. 1989. The Caribbean Community in Toronto. Toronto Department of Public Health, Health and Advocacy Section.

Societal Risk Factors and Access Issues

This section focuses on economic, social and institutional factors that affect the health of the Black and Caribbean Canadian community and its access to health care.

Doyle, Robert, and Visano, Livy A. 1987. A time for action: Access to health and social services for members of diverse cultural and racial groups in Metropolitan Toronto (Report 1 and 2). Social Planning Council of Metropolitan Toronto.

Fraser, Rose. 1997. Building black women's capacity on health.

Issac, Barbara. 1991. Exploratory study of health needs in the Black community. Toronto: Department of Public Health.

Kendall, P.R.W. 1992. Pilot study of the health and social needs of the Somali community in Toronto. Toronto: Department of Public Health.

Kobayashi, Audrey, and Moore, Eric. 1998. Healthy immigrant children: A demographic and geographic analysis.

Mathew, Sylvia, and Carter, Maxine. 1997. A non-shelter response to violence: An alternative model.

Matsuda, Atsuko, and Sorenson. 1991. Ethnic identity and social service delivery: Some models examined in relation to immigrants and refugees from Ethiopia. *Canadian Social Work Review*. 6(2): 255-268. Report on the Intercultural Community of the Black Community.

McGill Consortium for Ethnicity and Strategic Social Planning. 1997. Canadian Black communities demographics project.

Metropolitan Toronto. 1996. Demographic analysis of the African Canadian community in Metropolitan Toronto.

North End Community Health Centre. 1998. Our time reclaiming our health: Self-empowerment training for Black women.

Perrin, Burt. 1998. How does literacy affect the health of Canadians: A profile paper. Ottawa: Health Canada, Policy Development and

Coordination Division, Health Promotions and Programs Branch.

Silvera, Makeda. 1994. Black women organize for health. In *Women health sharing*. Enakshi, Dua, Fitzgerald, Maureen, Gardner, Linda, Taylor, Darien, and Wyndels, Lisa, eds. Women's Press.

Simms, Glenda. 1996. Aspects of women's health. Canada-U.S.A. Women's Health Forum.

Touch Base. 2000. Fight racism in health care. Nova Scotia's Multicultural & International News Monthly. 2(5).

Women's College Hospital. 1998. When day and night are reversed: Shift work and your health. *Women's Health Matters*.

Autoimmune and Genetic Disorders

This section examines disorders affecting the Black and Caribbean Canadian community. The publications reviewed also provide information on the access of members of the community to resources within the Canadian health care system.

Bureau for AIDS. 1990. Aids education and prevention in ethno-cultural communities: Report on National Consultation Meetings. December 1989-January 1990.

Bownman, James E., and Murray, Robert F. 1990. Genetic variations and disorders in people of African origin.

Canadian Sickle Cell Society. Sickle cell anemia. http://www.familyvillage.wise.edu/lib_scd.htm

Canadian Sickle Cell Society. Sickle cell anemia, the unchallenged disease: Know the facts.

Lupus Society of Canada. *Lupus Canada Bulletin*. <http://www.lupuscanada.org>

Lupus Society of Hamilton. <http://www.bestnet.org/~lupus/>

Serjeant, Graham. R. 1992. *Sickle cell disease*. Toronto: Oxford University Press.

Remis, Robert S., and Whittingham, Elaine P. 1999. The HIV/AIDS epidemic among persons from HIV-endemic counties in Ontario, 1981-1998 situation report.

Women's College Hospital. 1997. *Women's Health Matters*. 3(10): 1-2.

Chronic Diseases

Publications in this section provide information on the effect of chronic diseases such as diabetes, hypertension, heart disease and stroke, on the Black and Caribbean community.

Canadian Diabetes Association. Diabetes facts. <http://www.diabetes.ca>

Heart and Stroke Foundation. Heart and stroke information and research. <http://www.hsf.ca>

Heart and Stroke Foundation. 1990. Women, heart diseases and strokes in Canada.

Pride. 2000. Caribbean chapter of the Canadian Diabetes Association now a reality.

Pride. 2000. Suffering from diabetes? Help is on the horizon.

Weksler, Marc E. 1997. Obesity and diabetes: Research points to genetic connection. *Geriatrics*. 52(2): 57-64.

Cancer

The following publications focus on breast and prostate cancer and the Black and Caribbean community. They also address the community's access to related health care.

Black Women's Health Program. 1997. Breast cancer action Nova Scotia: Bridging the gaps.

Bottorff, Joan L., et al. 1999. Breast health practices and South Asian women. *Canadian Nurse*. 95(9): 24-27.

Canadian Cancer Society. <http://www.cancer.ca>

Mental Health

This section examines mental health issues in the Black and Caribbean Canadian community related to psychological disorders and addiction. The publications that were reviewed highlight cultural and racial issues surrounding diagnosis and access to treatment.

Across Boundaries: An ethnoracial mental health centre. <http://www.web.net/~acbound/>

Alexander, Sharon. 1990. Norms and differences of cultural groups in drug abuse education. In, *Substance abuse curriculum resources: Concepts*. Alexander, Sharon, ed. Victoria, B.C. 323-338.

Canadian Mental Health Association. 1995. Handbook on cross-cultural counselling.

Canadian Task Force on Mental Health Issues Affecting Immigrants and Refugees. 1988. After the door has been opened: Mental health issues affecting immigrants and refugees.

Centre for Addiction and Mental Health. 1999. Needs assessment for Ethiopian immigrants in Toronto. Haile Fenta, Research Co-ordinator.

Centre for Addiction and Mental Health. 2000. Pathways and barriers to mental health care for Ethiopian immigrants in Toronto. Haile Fenta, Research Co-ordinator.

Halton-Peel District Health Council. 1999. The Halton-Peel addiction treatment plan for integrated services.

Louden, Delroy. 1991. The epidemiology of depressive symptomatology and parental bonding in West Indian adolescents. Unpublished thesis.

Paniagua, Freddy. 1998. *Assessing and treating culturally diverse clients*. Sage Publications.

Stanley, Sue. 1992. Ethnicity and mental health: Research and policy issues. *Journal of Social Issues*. 48(2):187-205.

York Community Services. 1999. Needs assessment for Somali immigrants in Toronto.



Appendix A:

List of Organizations and Individuals Consulted

Organizations

Darcy Gray
African Men's Health Group
Halifax, Nova Scotia

Steve Benton
African Men's Health Group
Halifax, Nova Scotia

Scholastica Lyanga
Board of Directors
Windsor Women Working with Immigrant Women
Windsor, Ontario

Esther Tharao
Women's Health in Women's Hands
Toronto, Ontario

Joyce Ross
Executive Director
East Preston Day Care Centre
Halifax, Nova Scotia

Abukar Moalim
York Community Services
Toronto, Ontario

Dr. Haile Fenta
Centre for Addiction and Mental Health
Toronto, Ontario

Ileen Howell
Markham Caribbean Association
Markham, Ontario

Agatha Mason
Lawrence Heights Community Health Centre
Toronto, Ontario

Dolly Williams Regional Representative
Congress of Black Women of Canada
Halifax, Nova Scotia

MaryAnne McKinnon-Rodrigues
Executive Director
Metropolitan Immigrant Services Association
Halifax, Nova Scotia

Joanne Henderson-White
Metropolitan Immigrant Services Association
Halifax, Nova Scotia

Juanita Smith
Executive Director
Black Coalition for AIDS Prevention
Toronto, Ontario

Denise Brooks
Executive Director
Hamilton Urban Core Community Health Centre
Hamilton, Ontario

Jemell Moriah
Cornwallis Baptist Church
Halifax, Nova Scotia

Brian Kersey
Windsor Urban Alliance
Windsor, Ontario

Joanne Veldhorst
London Intercommunity Health Centre

Individuals

Susan Edmonds
Psychiatric Nurse (retired)
East Preston
Halifax, Nova Scotia

Judith Miller
Physiotherapist
Windsor, Ontario

Mathew Thomas
Preston Area Board of Trade
Halifax, Nova Scotia

Bruce Peterkin
Health Professional
Hamilton, Ontario

Bonnie Williams
Halifax, Nova Scotia

Lorraine Thomas
Co-Ordinator of Disabilities Program
The Hospice
Windsor, Ontario

Mavis Appiah
Nursing Student
Windsor, Ontario

Khadija Ali
Intergenerational Project Assistant
Windsor Women Working with Immigrant Women

Maxine Carter
Health Consultant
Hamilton, Ontario

Dr. Patrice Miller
Windsor, Ontario

Dr. Dana Watson
Hamilton, Ontario

LaFerne Clarke
Executive Director
Big Sisters of Kitchener-Waterloo
Kitchener, Ontario

Report on Strategic Planning Workshop on Black and Caribbean Canadian Health Promotion

*Ottawa, Canada
March 23-24, 2001*



Strategic Planning Workshop

Executive Summary

The Canadian Centre on Minority Affairs (CCMA), with the financial support of Health Canada, organized and hosted a national meeting on the health concerns of the Black and Caribbean population of Canada.

Using their year 2000 study, *Health Promotion and Population Outreach in the Black and Caribbean Canadian Community*, as the basis for discussion, the CCMA brought together health organizations and charities, academics, volunteer agencies, cultural organizations, community-based service providers, with an interest in the health needs of the Black and Caribbean community in Canada.

The overall goal of the meeting was to improve awareness of the health issues of relevance to the Black and Caribbean population in Canada, and to determine if there was a common interest in pursuing collaborative action on health promotion for this population.

The meeting covered specific health issues of particular relevance to the Black and Caribbean population, such as prostate cancer, hypertension, diabetes, and sickle-cell anemia, systemic issues such as racism, barriers to health, health status indicators and risk factors, access to health care, and certain overriding issues such as women's health, men's health, research priorities, funding, cultural determinants, socio-economic status, and participation and capacity building.

In summary, the meeting determined there was a considerable need to address health promotion for the Black and Caribbean population in Canada, and great merit (as well as interest) in working in a collaborative way across the country, to learn, share experiences, knowledge, and information, and to develop national strategies for action that would be implemented at the local, regional, or national level, and would improve the current and future health of the target community.

The meeting appointed a small working group to continue to take the next steps as outlined in a preliminary plan of action and specific work plan.

Background

In 2000, the CCMA conducted a study in Nova Scotia and Ontario on the health issues of concern to the Black and Caribbean population in Canada.

The report, *Health Promotion and Population Outreach in the Black and Caribbean Canadian Community*, recommended action in the areas of research on health determinants, health status; the education and training of service providers on the cultural, physical and community-specific conditions of the Black and Caribbean Canadian community; development of a cohesive policy approach to the health needs of this community; building of the capacity of the sector to deliver culturally appropriate services and of the community to develop partnerships with health care providers and Researchers; increased representation of the Black and Caribbean community in the sector; provision of support and resources to assist organizations to undertake local, regional, and national projects consistent with the health needs and priorities of the Black and Caribbean community; support of advocacy activities on behalf of the community.

Following discussions with Health Canada, funding was made available for a small meeting of interested representative stakeholders to pursue the recommendations in the report through a discussion of, and delineation of, collaborative action in the national context.

Participants

A wide range of individuals and organizations attended the meeting. They represented service delivery organizations, cultural groups, academics, national health organizations, and government. A list of attendees follows.

Objectives

The objectives of the workshop were aimed at beginning the process of moving the information from the research paper out into the community of interested organizations, and taking the first steps toward collaborative action to improve the health of the Black and Caribbean population in Canada. The original objectives were as follows:

- ◆ To raise awareness about the health of the Black and Caribbean population in Canada;
- ◆ To discuss the findings in the report, *Health Promotion Outreach in the Black and Caribbean Canadian Community*, with key stakeholders including health care providers, national organizations, community experts, academics, and governments;
- ◆ To prioritize the report's recommendations on addressing the health concerns of the Black and Caribbean Canadian community;
- ◆ To identify strategic directions for the top recommendations and begin to develop objectives, identify responsibility, and draft a work plan;
- ◆ To prepare a final report including a draft work plan.

Projected Outcomes

It was hoped that the meeting would produce the following results:

- ◆ A meeting of key stakeholders to discuss the health of the Black and Caribbean Canadian community;
- ◆ A final report of the meeting structure, process, outcomes to Health Canada;
- ◆ Recommendations for strategic directions to improve the health of the Black and Caribbean Canadian community, recommendations related to health access and service delivery.

Discussion

The meeting was structured in three parts.

- ◆ The first part was to raise the general level of awareness of the health issues and recommendations contained in the report, *Health Promotion and Population Outreach in the Black and Caribbean Canadian Community*.
- ◆ The second was to put these health issues into a strategic context, outlining the underlying causes of certain health access issues and capacity inadequacy matters and to offer some examples of work taking place at the community level, and to present some information on funding available to address the overarching issues as well as specific health problems.

- ◆ The third part was, through small workshop sessions, to give the participants the opportunity to define the issues and develop strategies for collaborative action that would address the systemic issues as well as the practical service delivery problems. The participants would then come together again and evaluate the information from the small groups and outline the health indicators that would serve as the foundation for concerted action in the future, and then provide priorities for action.

This brief document only provides detailed reporting on the results of the discussion as it emerged from the facts of the information-sharing in the first two parts of the meeting, and the general strategic directions given by the meeting and to be undertaken by the CCMA.

Outcomes

The meeting made a number of suggestions for possible collaborative and supportive action in the future. Under the general direction of the CCMA, a small working group is to take the next steps to follow up on the directions given at the meeting.

Influencing Factors on Black Health

The meeting identified the following influencing factors to the working group and any eventual mechanism that directs or influences the future direction of health care work for the Black and Caribbean Canadian population:

1. That the health system operates within the shared jurisdiction of the federal/provincial and territorial governments, and that municipalities also have a role to play;
2. That access to adequate care and good health and health promotion, and the existing chronic poor health of many in the Black and Caribbean community, is very directly a function of socio-economic status and levels of literacy;
3. That optimum health is shaped by cultural imperatives that influence the individual's interface with the health care system (how and if the person approaches health practitioners, their attitudes to the formal health care system, their ongoing follow-up to medical advice, their care of family members, and the health care system's understanding of the particular health issues, concerns, socio-economic

status, literacy – both actual and medical, and cultural beliefs and attitudes, the health care system’s ability to deliver appropriate care in appropriate language, and racism in allocation of funding for research and in service delivery and design);

4. That health care for the Black and Caribbean community in Canada is very much affected by what is seen as systemic racism across the sector;
5. That there are very specific health issues for women, as well as for men, and that these relate not only to specific diseases, but to culturally imposed attitudes and behaviours that affect good health;
6. That health determinants are very much amplified by the stress faced by the individual, in terms of the physical and mental violence they experience in the family and from the racism in society;
7. And that no approach to improved health care for the Black and Caribbean population in Canada can be effective without approaching it in a holistic manner that integrates all these factors, and social justice demands no other approach.

Priority Issues

The requiring implementation actions for health were given the following priority at the meeting:

- a) Establishing a national network on Black health;
- b) Developing and influencing a national health agenda;
- c) Funding for health initiatives;
- d) Conducting research on health issues and on the target population.

In addition, the following areas were identified as part of the overarching strategy to meeting the health care needs of the Black and Caribbean community:

1. Building a national database;
2. Building partnerships;
3. Advocacy and lobbying;

4. Establishing a think tank;
5. Monitoring and tracking of research, trends, health statistics;
6. Information/communications/education.

The three subgroups made the following comments when they identified the issues and strategies for addressing those issues:

- ◆ They wanted to ensure the nomination of a working committee to start planning a national black health organization or network before they left the meeting;
- ◆ This would begin with the formation of a working group with specific tasks, which would eventually become the national advisory group on Black and Caribbean health;
- ◆ Information, communication, and education were deemed a priority, not only for the Black and Caribbean Canadian population, but for the health services and research sectors and governments;
- ◆ A health newsletter might be one way to develop linkages across the sectors and the country;
- ◆ A database would provide a proactive source of information for the community, health and research professionals, on health issues and practitioners and community organizations with best practices to share and expand;

As a follow-up to the presentation by the Canadian Institutes of Health Research (CIHR), there was great interest not only in influencing, and developing a methodology for influencing the national health research agenda, but also in creating a Black Health Institute in the CIHR.

Accountability, and the development of mechanisms to ensure it, were also seen as important, not only regarding the research agenda, but also for decision-makers to ensure the needs of the Black and Caribbean Canadian community are well respected.

There was considerable discussion on literacy, not only the adequate ability to read and write as it pertains to health, but the development of culturally appropriate information, training, and service delivery so that health care professionals are working in the cultural language of the recipient of their services.

Underlying some of the barriers to access to health care is the question of helping the Black and Caribbean people in Canada to “value ourselves”, such issues as self-esteem, macho attitude, self-education, and assertiveness were raised as relevant. The Black and Caribbean Canadian population needs to learn to be more assertive when communicating with health services and when defining health issues.

Part of the accountability and access discussions focused on influencing the policies of the institutions, their processes for allocation of resources, and having Black and Caribbean people sitting on decision boards.

Part of an effective and comprehensive research agenda should include suggested ways to monitor and track health issues such as prostate cancer, diabetes, breast cancer, hypertension, sickle-cell anemia, HIV/AIDS, lupus, and tuberculosis (linked so closely with poverty).

The role of unions as supporters of, and voices for, Black health issues was also mentioned as an issue to be addressed.

Timelines

While the working group is to initiate work on all the areas identified, the participants at the meeting gave the following general timelines for the working group to move toward:

- ◆ Immediately form a small working group to take the next steps in the work;
- ◆ Over the next three months, to establish the necessary contacts across the country to become representative of the most significant interests and all the regions where the health needs of the Black and Caribbean population are of concern; and to develop an options paper on the establishment of a national network on Black and Caribbean Canadian health;
- ◆ Within six months, to provide feedback to the core group on the development of a network and a database, options for establishing and influencing a national health agenda, funding availability for health initiatives, and an approach to the identification of research needs on health issues and the target population;
- ◆ Within the first six months to develop a planning document for the First National Black Health Conference;

- ◆ To hold the conference in about one year at which time a national Black health network will be launched.

Evaluation Comments

All but one of the evaluation comments received indicated that the workshop was very effective or extremely effective in improving the participants' awareness of the health issues for the Black and Caribbean Community. All but two of the respondents said they understood the objectives of the meeting and had an adequate opportunity to participate. While most believed the relevant issues had been addressed and that the meeting was very informative, several indicated they understood that given the time constraints there was a need for additional subjects to be addressed at some future time.

Additional comments included inviting a larger selection of organizations for a future meeting, spending more time addressing specific health issues, and the need to expand the CCMA study to cover other areas of the country. Other issues to be addressed in the future included: leadership in the Black community, poverty as it affects health, a national database and networking. There was a request for strong follow-up to the work begun.

List Of Participants

Brooks, Denise

Hamilton Urban Core Community Health Centre

Providence, Bert

Bloor/Gladstone Library Literacy for East Toronto

Oliver, Karl

West Indian Social and Cultural Society

Thomas, Barbara

Jamaican Canadian Association

Otto, Judith

Volunteer Coordinator/Black Coalition for AIDS Prevention

Johnson, Eunadie

Women's Health in Women's Hands

Aitkens, Andrew

Canadian Public Health Association

Engdasaw, Abebe

Canadian Public Health Association

Marks, Alan

Canadian Diabetes Association

Lawrence, Derek

Ontario Coordinator, Canadian Prostate Cancer Network

Salah, Ebyan

Somalian-Canadian Institute of Research and Development

Charles, Keith

Black Canadian Scholarship Fund

Kalumba, Jayne

Canadian African Women's Organization

Gray, Darcy

African Male Health Network

Casavant, Nina

Women and Children's Health

Henry, Carol

College of Pharmacy and Nutrition University of Saskatchewan

Sealy, Jonathan

Saskatchewan Indian Federated College

Shade, Casper

Grenada Association of Manitoba

Cadogan, Rosetta

Canadian Sickle Cell Society

Sanon, Wilson

Regroupement des parents d'enfants souffrant de maladies falciformes

Braun, Maureen

Congress of Black Women

Winn, Paul

Black Historical Society of British Columbia

Gordon, Xania

Health Canada

Hicks, Susan

Health Canada

Plante, Helen

Canadian Institutes of Health Research

Wood, Diane

Drinkwater Consultants

Francis, Ian

Canadian Centre on Minority Affairs

Hayle, Maxine

Canadian Centre on Minority Affairs



Part IV Toward Cultural Competence

Document 1

Introduction to Cultural Competence in Pediatric Health Care

November 2000

Document 2

Cultural Competence in Pediatric Health Care
Report of Proceedings of the National Workshop on Current
Practices and Strategies in Pediatric Health Care

November 2000



Introduction to Cultural Competence in Pediatric Health Care

November 2000

This is an abridged version of the original report.



Introduction to Cultural Competence in Pediatric Health Care

Introduction

For years, Canadians have looked with pride to their health care system, as a national symbol of our collective values. There is room for improvement, however, in the provision of Canadian health care. For example, culture can play a significant role in the accessibility of health care and as a result it is essential for health care providers to demonstrate cultural competence. In order to fulfill the principles of the *Canada Health Act* and satisfy the health care requirements of a diverse nation, the meaning and relevance of cultural competence in health care must be addressed.

The *Canada Health Act* is the framework for health care in Canada. This pivotal piece of legislation stresses the importance of access to health care for all citizens. As such, one of the five principles of the *Canada Health Act* is the principle of accessibility. Within the context of the *Canada Health Act*, this principle refers to financial barriers to health. However, the specific text does not fully embody the true meaning of accessibility to health care for Canadians. Other barriers such as the geographic distribution of the population, a lack of specialized health care providers and a lack of interpreters may also create a barrier to access. Further barriers are often the result of cultural differences that give rise to ineffective communication and misunderstandings. Limited communication often results in limited assessment and thus, limited treatment.

Communication is an essential aspect of health care. In turn, cultural competence is an important aspect of communication. In order to receive appropriate treatment of the highest quality, it is necessary for clients from all cultural backgrounds and linguistic profiles to be able to voice their individual needs, within their specific context, to a

health care provider. When information has been successfully communicated by the client and understood by the health care provider, there is greater likelihood that the client will be able to access and receive the necessary care.

In a health care setting, culture can influence communication through everything from language used and emotional responses to eye contact and touching. Culture encompasses many elements such as beliefs, attitudes, values, verbal communication and non-verbal communication^a. Culture may be influenced by a number of factors such as location, race, ethnicity and religion. Less obvious, but equally important influencers of culture are factors such as disability or sexual orientation. For instance, the hearing impaired have a unique culture, in that they possess their own language with non-verbal cues, which are specific to that group. Gay, lesbian, bi-sexual and two-spirit individuals are another example of a population that must be treated with cultural competence.

If health care providers are not competent in addressing cultural differences, this may limit their clients' access to optimal care. A competent individual is someone who has "requisite or adequate ability or qualities"^b. In other words, a competent health care provider requires a combination of skills, knowledge, attitude and judgement to effect a positive outcome in health care. *Cultural competence* is defined as the "provision of health care that responds effectively to the needs of patients and their families, recognizing the racial, cultural, linguistic, educational and socio-economic backgrounds within the community^c."

There are four elements to cultural competence^d:

- ◆ self-awareness and awareness of one's personal value system;

a The Southwest Regional Center for Drug Free Schools. 1992. Cultural Sensitivity Position Paper. <http://www.occe.ou.edu/swrc/culpos.html>

b Merriam-Webster. 2001. Merriam-Webster's Collegiate Dictionary, <http://www.m-w.com/home.htm>

c Masi, R. 2000. Report of Proceedings of the National Workshop on Current Practices and Strategies in Pediatric Health, p.8.

d American Association of Medical Colleges. 2000. Cultural Competency,

- ◆ understanding of the term culture and its place in a health care setting;
- ◆ sensitivity to the cultural issues of each individual client;
- ◆ comprehension and ability in using specific methods to deal with cultural issues.

Cultural competence also requires a firm understanding of one's own culture. By combining these elements, health care providers help to bridge the gap between themselves and their clients. Increased closeness in terms of understanding and mutual respect will serve to increase the client's access to the best possible care.

In light of the diversity of the population, the application of cultural competence in health care relationships holds particular relevance in Canada. Demographic figures gathered by Statistics Canada provide evidence of the non-homogenous nature of the Canadian population and thus reinforce the necessity of a culturally competent health care system. Canada is a country with citizens from various cultural backgrounds. The 1996 census conducted by Statistics Canada identified the ethnic diversity of the Canadian population. Of those reporting only a single ethnic origin, approximately two-thirds of respondents claimed to be of European origin and nearly one-third simply claimed to be of Canadian origin. Of the respondents reporting more than one ethnic origin, the most common origins were Asian, Aboriginal, Caribbean, Arabian and African.

Canada also has a sizeable immigrant population. The total number of immigrants between 1961 and 1996 was 4,971,070^e. The ethnic composition of the immigrant population has been dynamic over the years. In 1957 the top ten source

countries of immigrants were European; whereas, in 1997, eight of the top ten were non-European^f. Furthermore, in 1999, the top three regions of origin were Asia and Pacific (51%), Europe and the United Kingdom (21%) and Africa and the Middle East (18%)^g.

Another factor, inextricably intertwined with culture is language. In her report, *Language Barriers in Access to Health Care*, Sarah Bowen recognizes that language is not the only cultural barrier in access to health care; however, language is the basis for further understanding^h. When the client and the health care provider can communicate on a basic level, this provides a foundation for a more positive health care interaction. The importance of language runs deeper than the necessity for health care providers to be able to work in one of Canada's two languages (French or English). The 1996 census showed that of the population reporting one mother tongue, 16.3% identified neither French nor English as that language. The three most common mother tongues reported, besides English (60.1%) and French (23.6%), were Chinese (2.5%), Italian (1.7%) and German (1.6%)ⁱ. The remaining 10% spoke several miscellaneous languages.

Given these statistics, it is clear that Canadians are not a culturally homogenous group. The *Canada Health Act* stresses the principle of access for all citizens. An understanding of the concept and application of appropriate knowledge, skills and judgement is pivotal to the care of culturally diverse clients. The application of cultural competence is essential if health care providers are to provide a high level of access to quality care within an effective and efficient health care system.

e Statistics Canada. 1996. Immigrant Population by Place of Birth and Period of Immigration, 1996 Census, Canada

f Kessel G. 1998. The Canadian Immigration System

g Citizenship and Immigration Canada. 1999. Facts and Figures 1999: Immigration Overview

h Bowen, S. 2000. Language Barriers in Accessing Health Care, p.2.

i Statistics Canada. 1996. Population by Mother Tongue, 1996, Census

Cultural Competence in Pediatric Health Care

*Report of Proceedings of the National Workshop on
Current Practices and Strategies in Pediatric Health Care*

November 2000

This is an abridged version of the original report.



Executive Summary

This workshop was organized by the Children's Hospital of Eastern Ontario's Multiculturalism Program to bring representatives from across Canada to meet, share, discuss and exhibit current practices and strategies for culturally competent pediatric care. This goal grew out of the recognition that health service providers across the country experienced common challenges in providing service in an increasingly culturally diverse milieu. Invitations were sent across Canada to hospitals and social agencies concerned with children's health. The workshop was attended by thirty-three participants from British Columbia, Alberta, Manitoba, Ontario, Quebec and Nova Scotia.

Participants in the workshop were sent a pre-workshop questionnaire, the results of which were used in planning the agenda. Participant responses highlighted concerns and current levels of knowledge regarding cultural competence. Dr. Ralph Masi, the keynote speaker, addressed these concerns by elaborating on the concept of cultural competence.

Participants discussed practices and strategies currently used and elaborated challenges that would be faced in making institutions culturally competent. These challenges were seen to exist at both organizational and individual levels. Participants provided displays of their institutions' programs and, in addition, three programs were highlighted in presentations by Suzanne Barclay of the Children's and Women's Health Centre of British Columbia, Heather Clarke of the Montreal

Children's Hospital, and Fanny Zegarra of the Children's Hospital of Eastern Ontario (CHEO).

To ensure that best practices be developed, participants explored the potential for the application of evidence-based research to the issue of cultural competence. This discussion was introduced by Lynn McCleary of CHEO.

After discussion, concrete action plans were developed to establish a nationwide network of links and to ensure the continuation of a process, which has the long-term goal of establishing practice guidelines for culturally competent services.

The following concrete actions were adopted by participants:

- ◆ A national clearinghouse of information will be established;
- ◆ A telephone and e-mail directory of all workshop participants will be maintained;
- ◆ A regular schedule of teleconferences has been set, focusing on issues related to development of best practices for culturally competent health care; and
- ◆ A conference is planned for 2001, focusing on the application of evidence-based research to cultural competence issues.

The organizers and participants of this workshop gratefully acknowledge the financial support of Health Canada, without whose assistance it could not have taken place.

Introduction

In recent years, Canadian communities have become more culturally diverse, a fact which has presented challenges to health care providers across the nation. Hospitals have increasingly recognized that cultural practices, values and expectations have an important influence on the provision of health care and have responded in many cases by adapting services and protocols to meet the individual needs of patients and families.

There is growing awareness that, in addition to showing cultural sensitivity in individual cases, health care providers should develop policies, procedures and practices that explicitly reflect the importance of cultural competence in health care. Some Canadian hospitals have begun to implement programming and services to support culturally competent practices. Unfortunately, these programs have been developed, for the most part, in isolation from each other.

This workshop provided a forum for health care professionals and other concerned parties from across Canada to meet, discuss and exhibit current practices and strategies in the delivery of culturally competent health care. Further, it produced a concrete action plan to establish an enduring network of links between institutions as a first step in the development of evidence-based, culturally competent practices, which will result in more inclusive care to patients and families nationally.

Pre-Workshop Questionnaire

Description

A pre-workshop questionnaire was sent to invitees to ascertain current practices of participating institutions, as well as to identify key concerns of participants and their perceptions of barriers to development of cultural competence. The questionnaire asked whether institutions currently had multiculturalism programs and included questions regarding both cultural competence and evidence-based practice. Eleven participants responded, out of 20 questionnaires sent.

With respect to cultural competence, respondents were asked to rank a number of activities/services according to how often they are accessed, how important they are in the development and maintenance of cultural competence, and their priority for improvement.

Regarding evidence-based practice, respondents were asked about their knowledge of evidence-based practice and how to implement research findings in practice. They were also asked to describe how evidence-based practice is facilitated in their organization.

Finally, respondents were asked to share their perspectives on potential barriers to the development of evidence-based multicultural health care.

Results

There was a general trend in the responses indicating highest importance to cultural interpretation and staff education. These activities were reported to be the most often accessed, and were ranked the highest in terms of their importance to the development of cultural competence and priority for improvement. Public education was among the least commonly accessed and ranked low in terms of perceived importance, at this time, to the development of culturally competent institutions.

Respondents perceived a number of factors as being barriers to the development of cultural competence in their organizations. Although there were a number of different formulations, responses related to limitations on both resources and knowledge of currently available services. It was suggested that a climate of fiscal restraint and current constraints on staff time and resources influenced organizational commitment to the development of cultural competence. As well, even when the need for more culturally competent practices was recognized, individual institutions were often lacking in knowledge of resources available to address this need.

In their statements of personal objectives for the workshop, respondents expressed concrete, well-delineated concerns. There was a general desire to have a commonly accepted definition of cultural competence and a sharing of information about specific issues and the concrete strategies currently employed to address them. This was particularly true for individuals from organizations without established multiculturalism programs.

Record of Proceedings

Welcome

Participants were welcomed jointly by representatives of the two supporting organizations: Ms. Susan Hicks, Senior Nursing Consultant in the Health Care System Division of Health Canada and Mr. Garry Cardiff, CEO of the Children's Hospital of Eastern Ontario (CHEO).

Ms. Hicks placed the workshop in the context of Health Canada's ongoing efforts to explore ways to make the health care system more responsive to the needs of minority and marginalized populations. She mentioned a number of projects currently underway, all intended to reduce barriers to health services, which may be encountered by members of marginalized groups. Among these were a number of initiatives aimed at improving health care access for children and youth, including the needs of various ethno-cultural communities. Ms. Hicks concluded by reiterating Health Canada's commitment to this workshop's objective of improving the cultural competence of health care providers, thereby making health care more readily accessible to all Canadians.

Mr. Cardiff noted CHEO's commitment to addressing the needs of minority communities, lauding the work of the hospital's own Department of Multiculturalism. Citing CHEO's vision, "Making a difference to children and youth", he expressed his support for the participants of this workshop, given their concern with making health care more accessible to children and their families.

Workshop Objectives

Responses to the pre-workshop questionnaire and participants' objectives as stated at the beginning of the workshop resulted in the articulation of four general objectives. These were as follows:

- ◆ To arrive at a more complete shared understanding of the concept of cultural competence as a basis for the development of appropriate strategies to achieve it;
- ◆ To elucidate current services and practices, which concretely address specific issues encountered in health care delivery;
- ◆ To develop a mechanism to ensure that the practices employed are indeed accepted as current best practices; and
- ◆ To generate a concrete action plan to establish an enduring network of links, which would facilitate education, exchange of information and future development of practice guidelines.

The first three objectives were addressed in three presentations.

Dr. Ralph Masi addressed the definition of cultural competence, and its importance in health care.

Presentations by the Children's and Women's Health Centre of British Columbia, The Montreal Children's Hospital and the Children's Hospital of Eastern Ontario described services currently offered in the institutions with established multiculturalism programs.

Lynn McCleary, Clinical Scientist, Nursing, at CHEO, defined evidence-based research and illustrated its potential applicability to issues of cultural competence in health care.

In responding to the presentations, participants elaborated potential challenges to the development of cultural competence in their institutions and suggested potential first steps in the process of making their institutions and individuals working in them culturally competent.

The fourth stated objective was addressed with a number of concrete action plans generated in plenary session.

Presentations:

1. Keynote Address: Dr. Ralph Masi : What is Cultural Competence?

Dr. Masi opened his presentation by outlining key elements of cultural competence that distinguish this term from the closely related concept, cultural sensitivity. Cultural competence refers to provision of health care that responds effectively to the needs of patients and their families, recognizing the racial, cultural, linguistic, educational and socio-economic backgrounds within the community. Such health care, in addition to being sensitive to the reality of patients' cultural backgrounds, should include clearly delineated objectives, standards, content and evaluation. The concept of cultural competence, therefore, involves not only attitudinal variables, but also consideration of cultural realities as integral to the

development of programs, procedures and practices.

In the context of cultural pluralism which characterizes Canadian society, culturally competent health care institutions are necessary to ensure equality of access to a culturally diverse population. The prevention of inequities in the delivery of health care acknowledges the responsibility of providing greater resources to those with greater needs, as well as different and more appropriate models of delivery to those who have difficulty accessing current services.

Dr. Masi pointed out that failure to address cultural factors when providing health care contributes to the marginalization of groups whose needs are not treated as integral to the development of the programs or services. This marginalization can result in groups or individuals being underserved by a system which fails to provide programs and services that meet their needs. In this context, the development of culturally competent institutions and individuals is necessary to ensure completely inclusive health care.

Culturally competent health care would address the following barriers to inclusive health care:

- Inappropriate service provision, resulting from inadequate recognition of racial, cultural, linguistic and educational backgrounds of communities being served;
- Insufficient cooperation and coordination between institutions, agencies and professionals providing service;
- Inaccessible facilities due to location and hours of operation;
- Inadequate financial resources; and
- Intolerant or insensitive attitudes.

Dr. Masi concluded that the development of cultural competence involved both knowledge and attitudes. In order to ensure culturally competent health care delivery, service providers must be knowledgeable about both cultural and biological factors that impact upon health care. Furthermore, health care professionals should appreciate the impact of their own specific cultural norms on their provision of service.

2. Panel Presentation: Paediatric Multiculturalism Programs in British Columbia, Ontario and Quebec

Presenters:

Suzanne Barclay, Children's and Women's Centre of British Columbia
 Fanny Zegarra, Children's Hospital of Eastern Ontario
 Heather Clarke, The Montreal Children's Hospital

One workshop objective strongly expressed by the participants was the sharing of information about programs and practices currently in place. In response, presentations were made by representatives of three multiculturalism programs. These presentations elaborated on the services and philosophies of the institutions involved.

The presenters, though representing institutions with established programs, expressed a commitment to ongoing development and stressed adaptability as being a key feature of their approaches. Services provided by these multiculturalism programs include:

- Staff Education and Development;
- Cultural and Linguistic Interpretation Services;
- Community Outreach and Liaison with Community Services; and
- Patient and Family Support.

It was stressed that the operation of these departments depended upon the development of systems to support provision of inclusive care and practice guidelines for service providers. Community involvement was felt to be important, particularly input from minority communities regarding development of appropriate service delivery models.

3. Presentation: Lynn McCleary : What is Evidence-Based Practice ?

Background

One of the objectives of this workshop was to address the perceived need to evaluate current practices, with the goal of eventually developing practice guidelines for the delivery of culturally competent health care. This objective was strongly supported by

participants during the workshop. Indeed, an overriding aspect of the workshop was the interest in current practices that have proven successful, and the desire that any practices adopted be supported by evidence if possible. It was felt that evidence-based practice might profitably be explored as a potential mechanism of addressing these concerns.

As well, responses to questionnaires indicated that for a significant proportion of those surveyed knowledge of evidence-based practice was limited. Therefore, this presentation provides information regarding its conceptual basis and explored the possibility of its application to the development of culturally competent health care. It defined evidence-based practice, elucidated its process and investigated barriers to evidence-based multicultural health care.

Presentation

Ms. McCleary presented a number of definitions of evidence-based practice, which had in common the integration of research evidence with clinical expertise to improve the quality of clinical judgements. She explained the process of doing evidence-based research, illustrating how it might be applied to issues of multicultural health care. She summarized a questionnaire response, regarding current methods of facilitating evidence-based practice in their institutions. These included:

- Dissemination of information;
- In-service, workshops, seminars and grand rounds;
- In the context of individual programs/departments;
- Use of professional advisors; and,
- Research regarding outcomes and client satisfaction.

Finally, Ms. McCleary enumerated known barriers to evidence-based multicultural health care, and presented a summary of barriers perceived by questionnaire respondents as existing in their institutions. The known barriers included:

- Racism, lack of cultural understanding;

- Limits to literacy and language knowledge of service users;
- Staff awareness and education;
- Insufficient evidence/research, knowledge of research and dissemination of research;
- Challenges in evaluating qualitative outcomes and outcomes for multiple family members;
- Lack of organizational will for evidence-based or multicultural health care; and
- Constraints on time and financial resources.

Highlights of Participant Discussions

Participant discussions focused on issues raised in pre-workshop questionnaires and statements of concern made at the beginning of the session. These included:

- a) Reaching a consensus in their understanding of cultural competence and elaborating challenges to its development in the participants' organizations;
- b) Identifying and prioritizing service components that should be developed, and elucidating first steps necessary to develop them;
- c) Establishing links among institutions to facilitate exchange of information and ensure continuance of the process of developing practice guidelines; and
- d) Setting out a concrete action plan.

a. Reaching a consensus in their understanding of cultural competence and elaborating challenges to its development in the participants' organizations

Following the keynote address, in which cultural competence was defined, participants discussed what they perceived to be the most significant challenges to developing cultural competence in their institutions. Responses clustered in two categories, which can be described as involving mainly either institutional or individual issues.

Institutional challenges include:

- Incorporating the concept of cultural competence into vision and mission statements, thereby making it integral to organizational planning.
- Obtaining administrative commitment to development of cultural competence. Given the perceived tendency of institutions to maintain the status quo, receiving administrative initiative and support to create structures to ensure implementation of policies was seen to be potentially problematic. In light of this, evidence to support such initiative was seen to be important.
- Providing adequate orientation and ongoing education to raise consciousness of cultural issues. Particularly in organizations where this would represent a new initiative, education and attitudinal change would require long-term commitment.
- Developing a profile of front-line staff more reflective of the cultural diversity of the community.
- Developing mechanisms to monitor service delivery and outcomes.
- Proceeding with a new initiative in a period of fiscal constraint and overburdened staff.

Individual challenges include:

- Encouraging the recognition of different cultural perceptions of the nature and causes of health and illness, which represents for some a radical shift in perspective;
- Developing self-awareness and being conscious of one's own biases;
- Developing interest and commitment among staff who are already experiencing significant demands upon them, given time and staffing constraints; and
- Identifying and prioritizing service components that should be developed, and elucidating first steps necessary to develop them.

b. Identifying and prioritizing service components that should be developed, and elucidating first steps necessary to develop them

Two services were most often cited in the pre-workshop questionnaire as being accessed most frequently and having the highest priority for improvement: cultural interpretation and staff education. This was reflected in the participant discussions, where they were once again felt to be the most important.

Discussion of first steps needed to develop these services, and to have cultural competence become an important agenda in health care organizations, was focused in three areas: the need for administrative and financial support, the need to build and share knowledge bases nationally, and the need to develop community links. To address the concerns the following steps were suggested for consideration.

- Initiate research within current programs and through the literature to ascertain indicators reflecting the impact of such programs on quality of care. They might include indicators of compliance, patient satisfaction, risk aversion and informed choice. Such information would provide a rationale to decision-makers.
- Position interest at senior management level. Risk management may provide an area in which to position the issue of cultural competence. Involvement of board members in the process was suggested as possibly helpful.
- Piggyback onto existing committees to create interest in cultural issues.
- Develop a series of telehealth presentations to enhance awareness of models and directions that have been taken to date. By targeting presentations to specific audiences, it can be ensured that content matches the audience. Participants could share what they have implemented or plan to implement and get feedback on challenges, barriers, outcomes and lessons learned.

- Establish a clearinghouse of resources, which would be available to all centres.
- Establish a nationwide web site for ongoing updates.
- Evaluate how services address community needs. This could include community-based qualitative research and forging partnerships in the community, including the establishment of Advisory Committees.
- Establish closer ties with community-based non-health care agencies, such as Children's Aid Society, which have interest in cultural issues.

c. Establishing links among institutions to facilitate exchange of information and ensure continuance of the process of developing practice guidelines

One of the key objectives of the workshop and a top priority of participants was the establishment of linkages that would ensure ongoing communication and sharing of information. The following suggestions were made to accomplish this.

- An Annual Conference on Cultural Competence. It was suggested that such a conference could be combined with existing conferences to reduce cost and increase participation. To maximize its educational potential, the annual conference could focus on selected topics from year to year.
- The use of telehealth resources and teleconferencing to provide education and information-sharing opportunities.
- Establishment of a central resource and information clearinghouse which would be updated regularly.
- Creation of a national phone and e-mail list.
- Establishment of a web site or inclusion of information on cultural competence on existing web sites.

d. Setting Out a Concrete Action Plan

The following action items were accepted by participants at the close of the conference. These were intended to strengthen links among centres and ensure continued commitment to developing cultural competence. These items represent a serious

concern, expressed by the participants of this workshop, that the workshop initiate a process resulting in health care delivery concretely experienced by providers and users alike as being more inclusive.

- A conference will be held, if possible, in association with the 2001 Canadian Association of Pediatric Hospitals Conference. The conference will focus on the Application of Evidence-Based Research to Cultural Competence Issues. A background paper dealing with the theme will precede the conference. In addition, there will be a pre-conference update for the participants of this conference to review steps taken. This action will be undertaken by Fanny Zegarra and Lynn McCleary of the Children's Hospital of Eastern Ontario.
- A regular schedule of teleconferences will be set. These teleconferences will be focused on concrete topics. The topic list will be prepared by Suzanne Barclay and Beth Stanger of the Children and Women's Health Centre of British Columbia. The initial teleconference will be scheduled by Fanny Zegarra.
- A national clearinghouse of information will be established under the direction of Suzanne Barclay. This will be updated, to provide ready access to information when it becomes needed.
- A phone and e-mail directory of all workshop participants will be maintained by Olive Wahoush, Program Director, St. Joseph's Health Centre, Toronto (e-mail: wahouo@stjoe.on.ca), to facilitate an exchange of information as it arises.

Presenters

Suzanne Barclay is the Manager of the Cross-Cultural Office for Care and Diversity at the Children's and Women's Health Centre of British Columbia. Suzanne has worked and studied internationally. She is the founder and president of a cross-cultural communication firm, which works with businesses to develop programs, services and systems that are culturally and linguistically appropriate for a diverse clientele. She is a member of the Board of Directors of Foster Parents PLAN Canada. She has a bachelor's degree in

Anthropology, and is currently completing her MBA from Queen's University.

Heather Clarke was hired to develop the Multiculturalism Programme at the Montreal Children's Hospital. She remains the coordinator of this programme and has been actively involved in the development of numerous aspects of the cross-cultural dossier such as staff development, interpretation and institutional adaptation. In the course of her work she has collaborated with the MSSSQ (Quebec's Ministry of Health and Social Services, the RRSSSMC (Regional Board of Health) and other institutions. Ms. Clarke has a BA with Specialization in Communications.

Dr. Ralph Masi is a practicing family physician in Toronto. He has long been involved in issues of multiculturalism and health care. Dr. Masi is the Founding President of the Multicultural Health Coalition and the Canadian Council on Multicultural Health. He has numerous publications in multicultural health.

Lynn McCleary is currently Clinical Scientist, Nursing at the Children's Hospital of Eastern Ontario. She is a Registered Nurse who holds

a Bachelor of Science in Nursing from McMaster University, a Master of Science in Clinical Epidemiology and Biostatistics, also from McMaster University. She previously worked in mental health, most recently as an outpatient therapist at Chedoke Child and Family Centre in Hamilton, Ontario. Ms. McCleary is a PhD Candidate in the Faculty of Social Work at the University of Toronto.

Fanny Zegarra is the Manager of Multicultural Programming at the Children's Hospital of Eastern Ontario. She has first-hand experience with issues of diversity as a staff nurse, occupational health nurse and educator. She lectures on cross-cultural health issues for medical and nursing students at Queen's University and University of Ottawa. She has participated in international health promotion initiatives with Oxfam Canada. Ms. Zegarra served as president of the Ontario Provincial Multicultural Health Coalition, and a Board Member of the Canadian Council on Multicultural Health. She has also co-chaired the Mayor's committee on Race, Ethnic and Aboriginal Issues.

Conclusion

Canada has overcome many financial barriers to health care and is ranked among the top nations in the world in terms of the health of its citizens. Nevertheless, inequities in access to health and health care exist and the health system is not as responsive as it could be to certain populations.

There is increased likelihood that individuals who belong to a certain population may be underserved. In other words, they may experience difficulties in obtaining needed care, receive less care or a lower standard of care, experience different treatment by health providers, receive treatment that does not adequately meet their needs, or they may be less satisfied with health care services than the general population.

Since 1999, Health Canada, through the Innovations in Rural and Community Health Fund, has supported initiatives, which have helped to shed light on the current situation of various minority and marginalized populations and their experiences within the health system. Clearly, there is still work to be done.

As demonstrated in the findings from the background papers and meeting reports in this publication, Canadians may face language, attitudinal and cultural barriers during their interaction with the health care system. Reportedly, this is true for both health care providers and recipients of health care.

Although numerous recommendations have been made, those most commonly cited call for:

- ◆ further research on factors other than income, which can affect access to health care;
- ◆ establishing funding for health initiatives, which address the needs of underserved populations, as well as exploring new ways of providing health care;
- ◆ improving the education and training of health care providers regarding specific health issues and cultural factors related to the health of minority and marginalized populations;
- ◆ recruiting health care providers from minority and marginalized populations;
- ◆ ensuring that equity and access issues are considered in program design and delivery through better linkages between government and community; and
- ◆ strengthening the capacity and organizational infrastructure of community organizations concerned about equity in health so that they are better equipped to participate in the policy development process.

These recommendations provide a direction and focus for future work on equity in, and responsiveness of, the health system to the health needs of minority and marginalized populations. It is anticipated that these reports and their suggestions for action will serve as a catalyst for further research, policy and program work on equity in health in Canada.



Common Recommendations — From All Papers and Reports

The recommendations that follow are excerpted directly from the papers and reports in this publication. Please see the individual sections for the rationale and discussion.

There are several recommendations that are common to the reports and papers, specifically:

- ◆ the need for further research on issues of access;
- ◆ improvements to processes for the education, training and recruitment of health care providers;
- ◆ the need to address access in program design and delivery;
- ◆ the need to strengthen organizational infrastructure; and
- ◆ the need to establish funding for research and health initiatives, and to explore new ways of funding health care.

Research

Virtually every paper or report spoke of the need for more research. For example, there were calls for research on the factors other than income that can affect access to health care in Canada. It was recommended that research explore the effects of the exclusion of language minorities from health research, and other issues such as the relationship between gay, lesbian, bisexual and two-spirited people and their health care providers, and on the economic benefits of using interpretative services for language minorities. There were also calls for research to identify indicators of cultural competence and quality of care.

Education, training and recruitment of health care providers

Every paper and report in this collection pointed to the need for improvements in the education and training or recruitment of health care providers, for several reasons. First, it was pointed out, health care providers need better training in the issues of underserved populations, such as immigrant groups, language minorities and the

gay/lesbian/bisexual/two-spirited community. There were calls for better relationships between the organizations providing such training and the community. Staff education was also seen as a means of providing care that is more culturally competent. Recruiting strategies for health care providers were recommended to provide better service to underserved populations, including the development and expansion of alternative health provider roles.

Program design and delivery

The majority of papers and reports contained recommendations for health care program design and delivery based on the core idea that there should be a better link between the community and those agencies or government departments developing policies and programs for health care. For example, for language minorities the recommendation was made that there should be strategies to assist communities and institutions to develop models of service delivery that included interpretation services where appropriate. Others noted a lack of policy concerning specific groups in the population such as gay/lesbian/bisexual/two-spirited people, and called upon the federal government to play a leadership role in this area. All the authors or participants spoke of the need for participation of the community and various groups in health care policy development.

Capacity building

Recommendations in this category ranged from the general to the specific. In terms of overall access to health care, for example, the recommendation was that because the traditional emphasis on physician and hospital services in Canada's health care system is a major barrier to equitable access to care, new approaches to health care provision be implemented such as community health centres and different capitation models. In more specific recommendations was the idea that information-sharing was key to capacity building and improving the ability of organizations to provide more equitable access to care. Financing was mentioned, as was the need

for access to information about issues such as language and the needs of specific population groups. In the area of cultural competence, the suggestion was made that if cultural competence were seen as a factor in risk management by senior management of health care organizations, there could be more commitment to achieving culturally competent care.

Funding

Recommendations concerning funding were common to all papers and reports in the collection. In general, there were calls to examine new ways of funding health care services, and in specific recommendations to provide funding for specific health initiatives to address the needs of underserved populations and for more research.

Synthesis of Recommendations from Each Report

Equity in Access to Health Care

Access to Health Services for Underserved Populations in Canada

Author: Sarah Bowen

The Need for Research

In Canada, much of the research on access has focused on the variable of income. While there is general recognition that other factors such as language/cultural barriers, lack of information or inappropriate services affect access, these concepts have not been critically examined in a comprehensive way.

Clearly, more research is needed; however, research must utilize appropriate methodology. Greater attention needs to be given to clearly defining the populations and aspects of success to be measured, and to developing operational definitions and methods appropriate to the research questions and the characteristics of the communities studied. In addition, partnership with, and participation of, the populations affected is essential.

Responses/Solutions

A. Recruitment and Training

Recruitment of providers, particularly physicians, has been a common response to problems of medical workforce supply, particularly in rural and remote communities. Two strategies can be applied to service provision for underserved populations: pre-service recruitment policies and post-training initiatives.

Pre-service initiatives: affirmative action policies for admission to training for health professions and development of special programs to facilitate access to medical training for members of underserved populations.

Post-training initiatives: focus on the recruitment and licensing of professionals trained in other countries.

Other responses:

Pre-service and continuing diversity education for providers: a commitment to teaching cultural competence and addressing prejudice and discrimination within the training environment is required if meaningful access is to be ensured for all patients.

Development and expansion of alternate health roles: development of expanded and alternate health roles has been proposed consistently to increase efficiency of health care services, and to potentially improve care to underserved populations.

Academic health centres: in addition to a crucial role in educating health professionals, academic institutions have played a direct role in provision of service to the underserved, particularly those in remote locations.

B. Program Design and Delivery

The complaint that services are not accessible, culturally sensitive or appropriate suggests a need to increase flexibility and creativity in program design and delivery.

Responses:

Development of linking programs: Create links between providers and communities including interpreter/cultural mediator programs and community outreach initiatives.

Population-specific health services: One approach is to develop services focused on specific populations, to be operated by hospitals, community health centres, public health departments or community-based, not-for-profit organizations.

Use of communication technologies (telehealth/telemedicine): This technology has particular utility in delivery education and care to remote locations.

C. Structure and Policy

Three areas of response are essential to addressing barriers to access: funding models, diversity policy development, and partnerships/participations with underserved groups.

Funder and provider payment: The traditional emphasis on physician and hospital services is a major barrier to appropriate and equitable and appropriate care. Both community health centres and capitation models have been proposed to improve participation in preventive programs.

Diversity policy development: Initiatives must be taken at the organizational level to improve access for underserved populations, including requirement for the use of trained interpreters, training and orientation of providers, personnel policies (such as the inclusion of cultural competence as a performance measure), and mechanisms for community accountability.

Partnership/participation: Establishing partnerships with community organizations, and developing strategies for increased representation at decision-making levels must also be improved in all sectors.

Removing Barriers II: Keeping Canadian Values in Health Care

Editor: Ralph Masi

This document is a report of the second symposium in the Removing Barriers initiative, and there are many recommendations included in the individual presentations at the conference. The participants developed a "Declaration" statement on values in the health system, which in the main promotes support for the five principles in the *Canada Health Act*. In summary, the Declaration recommends the following steps.

Inclusivity: there must be the same commitment to the full continuum of care as promised to all in the *Canada Health Act*.

Accessibility: accessibility to health services must be promoted by adapting and situating health care services close to the communities for which they are intended.

Networking, Collaboration and Cooperation: opportunities must be provided for networking, collaboration and cooperation between health professionals and their communities, and all

stakeholders across the country must work together towards the recognition of diversity and the implementation of inclusion.

Health Disciplines Education: education in all the health disciplines must include mandatory and evaluated content for the development of knowledge, attitudes, skills and judgement appropriate to the needs and care of vulnerable or marginalized communities.

Ongoing development: national, professional, community and health organizations must take on leadership roles to advocate health care for vulnerable or marginalized communities.

Language and Barriers to Health Care

Paper 1.

Report of Symposium on Interpreting in the Health Care Setting

Author: Luc Rochefort

Some Courses of Thought and Action

Comments in italics represent quotes from symposium participants.

Education

The importance of defining training and certification criteria stood out in the group's reflections.

The Children's & Women's Health Centre of British Columbia uses trained and untrained interpreters, as well as bilingual members of the team. We do not yet have the appropriate, concrete means to evaluate interpreters' skills.

However, interpreters are not always available in regional settings:

The assistance program for new Canadians trains its interpreters. The problem is finding skilled interpreters in a small community like the Sherbrooke region, and to train the care providers with whom they work.

When the refugees came from Kosovo, we didn't really have interpreters.

Health professionals must also be trained on the importance of interpreters, on cooperating with them and work methods to improve cooperation between care providers and interpreters.

It is also essential to train care providers to create a better relationship with interpreters.

It would also be a good idea to take advantage of conferences as a forum to discuss the issues linked to interpreting and the organization of services. This would improve recognition of the interpreting profession by peers and care providers, who do not always see the advantages of using trained interpreters. Conferences would raise participants' awareness of the potential impact of cooperation between care providers and interpreters.

Some documents that deal with cross-cultural health issues, such as the Ontario Nurses' Guide, could be distributed more widely.

Organizational Policies

There are no concrete laws or guidelines governing interpreting services. While it is possible for institutions to set up criteria that must be followed, there is no national standard. Lobbying must be initiated not only by the communities that benefit from interpreting services, but also by health care institutions and professionals.

National standards must be established. Recognition of the interpreter's profession must be justified by training, status certification and policies that provide real recognition within the health care network. It is necessary to find new avenues to promote interpreters' status via Canadian lobbying. Furthermore, the Royal College of Physicians and Surgeons of Canada is organizing the PROMED project aimed at improving doctor-client communication. Lobbying efforts should be made in the same direction. In striving for excellence, one must first strive for quality.

It is essential to use interpreters if we want to guarantee the right to access to health care. The problem must be addressed at the national level.

Funding and Paying for Services

Canadian legislation is not very clear about the obligation of health care institutions to provide or pay for professional interpreting services for their clientele.

In the early seventies, the University of Toronto offered a two-year diploma in interpreting. The lack of jobs in that area forced the university to cut the program.

There is no specific law in Canada, and no concrete guidelines with regard to interpreting services.

For this reason, public institutions use trained and untrained interpreters, as they see fit.

The Institut universitaire de gériatrie de Montréal uses a bank of volunteers for interpreting services. We also use family members and bilingual staff to act as interpreters.

At the Grace Health Centre for Children, Women & Families, we have certified interpreters who have been trained at the cultural and language level.

In Quebec, the Ministry of Health and Social Services and the regional boards finance interpreters' banks, and public institutions pay for interpreting services on demand. However, regardless of the province, financing remains a problem.

Theoretically, in British Columbia, access to interpreting services is available to the population upon request. The problem lies with financing the service and paying interpreters. There has to be a proven increase in demands for service in order to obtain funds.

For their part, private clinics rarely use trained interpreters.

Research on potential lawsuits would make it easier to measure risk management, which could eventually lead to the spread of interpreting services.

Cooperation among Associations

Members must increase pressure on their representatives to make leaders aware of the need for interpretation services. Interpreters' contribution to improving communication with users and providing better care should be an integral part of associations' ethical principles.

Furthermore, health care professional associations must agree on the future of interpreters, and put pressure on institutions and governments to free up research grants and adequate funding for interpretation services. Coordination among Canada's various organizations could take place under the aegis of an association such as the Canadian Deafness Research and Training Institute or Critical Link Canada.

Research

There is a notable lack of data that could be used to justify setting up interpretation services. The Regional Office of Health and Social Services in Montreal Centre is awaiting statistics on users' mother tongues and the percentage of allophones who use CLSCs. It will then be possible to draw a correlation between this percentage and the total population in each area, and perform a better needs assessment. Organizations and institutions must record at reception the clients requiring the presence of an interpreter. A number of research projects could be carried out to determine the cost of establishing services, the various groups likely to benefit from the service, the complex nature of the situation, the cultural aspect of communication in a health care setting, etc.

In addition to the costs outlined in Ms. Bowen's presentation, the long-term economic repercussions could be the object of research. In order to achieve this, national lobbying should take place to free up funds for research on interpretation services and their impact on the health care network. Fundraising should not be limited to the federal or provincial government; university institutions and professional associations should also be targeted.

The following priorities stand out in the synthesis of Ms. Bowen's text:

- ◆ An analysis of Canadian approaches aimed at setting up applicable standards for health care institutions. In the United States, major initiatives are currently under way to define standards regarding cultural skill, including access in terms of language, but they are part of U.S. legislation, regulations and standards. Initiatives in Canada must be supported in order to continue.
- ◆ A more detailed analysis should be carried out on the issue of language access rights in Canada.
- ◆ It is necessary to establish guidelines for researchers regarding the complexity of research in this area.
- ◆ Finally, funding for research projects should be increased.

Paper 2.

Language Barriers in Access to Health Care

Author: Sarah Bowen

Based on a review of the literature the following recommendations are proposed by the author:

- ◆ Examine the feasibility of incorporating, as part of health system data collection, information on patient proficiency in official languages.
- ◆ Include, wherever possible, proficiency in an official language as a variable for analysis in health services research. This should always occur when ethnicity is one of the factors to be considered.
- ◆ Include in the review of health research proposals an assessment of whether those who are not fluent in an official language are eligible to participate, and promote inclusion of language minorities in both clinical and health services research.
- ◆ Develop strategies to increase health researcher awareness of the effects of exclusion of language minorities from health research, and methodological and ethical issues related to conducting health research with participants who have limited official language fluency.
- ◆ Develop initiatives to promote awareness of the importance of provider-patient communication, and the profession of interpretation within the health professions. Promote training on the effects of language barriers and working with interpreters as a required component of pre-service professional preparation.
- ◆ Develop strategies to promote dissemination of research on language access to policymakers and health service planners.
- ◆ Develop strategies to assist communities and institutions to develop models of service delivery appropriate for the variety of settings where interpretation is needed.
- ◆ Develop a coordinated national research strategy to further understanding of the impact of language barriers on health service utilization and health status of Canadians.

- ◆ Establish a centralized “clearinghouse” capacity for information and research on language barriers and language access programs in Canada.
- ◆ Develop a national strategy for health interpreter training, interpreter accreditation and standards of service provision.
 - Develop national standards of practice and appropriate models of service for the Canadian environment.
 - Coordinate strategies for training and accreditation of interpreters.
 - Include and coordinate strategies for official language, Aboriginal, visual, and immigrant languages.

Barriers and Specific Population Groups

Paper 1.

Access to Care: Exploring the Health and Well-being of Gay, Lesbian, Bisexual and Two-Spirit People in Canada

Authors: *Bill Ryan, Shari Brotman, Bill Rowe*

The following set of recommendations emerge from the cataloguing of gaps and dilemmas that exist within the international and Canadian research on gay, lesbian, bisexual and Two-Spirit (GLBT-S) health care access as well as from the documented experiences of these groups and their allies who participated in the focus group discussions. Each of these recommendations is predicated upon the need for collaboration between health care providers, policy makers and GLBT-S communities.

1. Concerning the Education and Training of Health and Social Service Providers

The historic role that the health and allied health professions (most notably medicine, nursing, psychiatry, psychology, sexology and social work) have played in the pathologization of gay, lesbian, bisexual and Two-Spirit people as deviants places a special onus on these professions, and their educators, to right these wrongs.

Recommended:

- That professional schools across Canada recognize that lack of training on issues related to GLBT-S health has further marginalized these communities and led

to them being in situations of greater health risk.

- That this lack of training on GLBT-S health and well-being issues be redressed through course content, research and consultation with these communities.

2. Concerning the Continuing Education of Health and Social Services Providers

Those professionals already in the field have received biased views of gay, lesbian, bisexual and Two-Spirit people, or were trained when the discourse of pathologization had been replaced by total silence.

Recommended:

- That a program similar to that of the Ministry of Health and Social Services of Québec be established, provincially and nationally, which has as its goals the correction of prejudicial attitudes towards GLBT-S persons, and the adapting of services to the needs of gay, lesbian, bisexual and Two-Spirit citizens.
- That professional associations across Canada be sensitized to the alienation felt by GLBT-S people regarding the health care system and providers, with the view that these associations implement policies and training programs to sensitize their members.
- That health care organizations representing Aboriginal communities and professionals be sensitized to the needs of Two-Spirit people within their communities and in urban areas.

3. Concerning Adapting Services to the Needs of Gay, Lesbian, Bisexual and Two-Spirit People

Gay, lesbian, bisexual and Two-Spirit people have all the health and well-being concerns of any citizen of Canada. However, they have the added challenge of facing current and historic mistreatment by the health care system. This has led to the mistrust of health care and social services by gay, lesbian, bisexual and Two-Spirit people.

Recommended:

- That public sector health and social service institutions must begin to evaluate their “state of readiness” to provide gay-positive health care services to

diverse GLBT-S individuals and communities. Initiatives must be put in place, which address systemic, institutional and individual barriers to appropriate and sensitive care.

- That specialized services that respond to the unique health and social service needs of GLBT-S people must be developed and supported as allies to the public health care system. These services could include, but are not limited to: support to youth who are in the process of coming out, support to parents of GLBT-S youth, support to GLBT-S persons who are parents, services that offer education and training to sensitize the broader community (schools, professional schools, health care providers, etc), community mental health services, seniors organizations, suicide prevention programs, etc.
- That health and social service organizations need to be sensitized to the fact that GLBT-S people have varying levels of unease when accessing services. There is a presumption by many, based on experience, that they must hide, or camouflage their sexual orientation in their interactions with health care and social service institutions and providers in order to receive adequate and equitable care. Organizational policies and services that take this fact into account and explicitly reach out to these populations do much to allay fears and build trust.

4. Concerning Policy Development

The absence of federal and provincial policy directives on gay, lesbian, bisexual and Two-Spirit people's health has contributed to access barriers and impeded the development of gay-positive health care services.

Recommended:

- That the federal government play a key leadership role in the articulation of best-practice regarding the health and well-being of GLBT-S people. This includes bringing recommendations for adapting services to provincial health ministers as well as assisting institutions and providers through the development of training programs, guides and other

materials on GLBT-S health and health care which can be applied across jurisdictions.

- That the federal government support research initiatives and demonstration projects addressing health care access and service delivery for GLBT-S people.

5. Concerning Research

Historically, research has been used to confirm prejudice, seek out the causes, and test treatments for "deviance". Recently, it has been limited to gay and bisexual men in the context of better understanding the vectors of the HIV pandemic. There is little, if any, research on the lives of gay, lesbian, bisexual and Two-Spirit people, the impact of stigmatization, the adapting of services, the impact of homophobia in health care, or how gay, lesbian, bisexual and Two-Spirit people live in Canada. This is particularly so in the case of lesbian and bisexual women and Two-Spirit people.

Recommended:

Research in the field of GLBT-S health and well-being

- That research funders be encouraged to explore the health and well-being of GLBT-S people and the question of access to care.
- That research be conducted on the relationship that GLBT-S people have with their health and social service providers and health and social service organizations.
- That research be conducted in partnership with GLBT-S people through all stages of the research endeavour.

Research in the field of lesbian and bisexual women's health and well-being

- That research be encouraged and funded to study the situation of lesbian and bisexual women in Canada – a population that has been widely ignored and is seriously lacking in the kinds of contacts that gay men have established with health care providers in the last two decades.
- That research be undertaken respecting the differences between gay and bisexual men and lesbian and bisexual women,

their understanding of health, their relationship with care providers, and their development of networks.

- That research be undertaken to better document the experiences of glb women from ethno-“racial” communities in relation to health and health care access.
- That research include the experiences and needs of bisexual women.

Research in the field of two-spirit health and well-being

- That research be undertaken to better document the lives and stories of Two-Spirit people, their relationship to their communities and to health and well-being.
- That Two-Spirit people be included explicitly in any policy formulation, research frameworks, outreach documentation or educational programs developed to increase access to care for gay, lesbian and bisexual people.
- That research include an analysis of the historic and current impact of colonialization on Aboriginal communities.

Research in the field of gay and bisexual men’s health and well-being

- That research into gay men’s health issues not be limited to epidemiology and the explicit vectors of HIV infection, but include interest in the lived experiences of gay and bisexual men, the impact of homophobia and heterosexism in their lives, their relationships with their communities, and their health care in general.
- That research be undertaken to better document the experiences of gay and bisexual men from ethno-“racial” communities in relation to health and health care access.
- That research include the needs and document the experiences of bisexual men.

6. Concerning the Place of Transgendered and Transsexual People

A recurrent theme in this study was the official absence of discourse concerning transgendered and transsexual people. Participants in the focus groups expressed consternation that the process was not inclusive of transgendered and transsexual people, and the literature review underlined the absence of data concerning their lives and their relationship with the broader gay and lesbian communities.

Recommended:

- That, as a follow-up to this study, a focus group be conducted to document the question of access to care for transgendered and transsexual people in Canada.
- That research be encouraged to look beyond the surgical and psychiatric aspects of transgenderism and transsexuality to see the persons who are transgender and transsexual, their lives, their experiences, and their relationship to health care in general, including mental health services.
- That, following discussions with this community, and with their consent, a collective decision be made as to whether subsequent initiatives be undertaken as gay, lesbian, bisexual, Two-Spirit, transgendered and transsexual inclusive.

7. Concerning Building Upon the Current Project: Developing A Phase II Initiative

Recommended:

That a second phase of this project be initiated to:

- Further explore the experiences of gay, lesbian, bisexual and Two-Spirit people (or GLBT-S and transgendered/transsexual people) across Canada by constituting focus groups in several additional Canadian locations.
- Expand the research to include the experiences of those who are not represented in the current project or who are under represented, such as: gay, lesbian, bisexual and Two-Spirit people who are not fully self-affirmed and those living in isolated and remote communities,

through a directed research program developed on the web with the support of gay and lesbian media.

- Duplicate the outreach undertaken with Two-Spirit people in Phase I with ethno-“racial” GLBT-S people by accessing key individuals who can facilitate the process of building trust with individuals in order to constitute focus groups in several communities.
- Establish a best-practices guide on GLBT-S health and well-being for use by service providers, institutions and professional associations across Canada, which would include an evaluation of their «state of readiness» to provide gay-positive services.
- Develop a training program, similar to that in use in Quebec, to be made available to other provinces.
- Create and test a model university level course on “Good Health and Good Care in Gay, Lesbian, Bisexual and Two-Spirit Communities” that will be made available to learning institutions across the country.

That these initiatives be undertaken in conjunction with the establishment of a National Working Group on Gay, Lesbian, Bisexual and Two-Spirit Health and Well-being.

Paper 2

Report on the National Meeting of Canadian Researchers in the Field of Gay, Lesbian, Bisexual and Two-Spirit People’s Health

Authors: Bill Ryan and Shari Brotman

Priority Issues for Research

Several areas were suggested as priority areas for future research. It is important to note that the participants do not consider this list to make up a definitive “research agenda”. Instead, this list is meant only to generate further discussion about themes, areas of concentration and current gaps in research. Also, several of the suggestions listed below relate not to areas for research but instead focus on areas through which research can be supported or enhanced. For example, participants discussed needing to improve environments to encourage interprovincial and interdisciplinary

research collaboration, dissemination and marketing of research, and training future practitioners in health in order to raise awareness of the importance of considering GLBT-S health as an important issue for practice and research.

Gaps in research on GLBT-S health were identified. For example, participants stated that, while some documentation exists on the impact of homophobia and heterosexism on health, there is far less information available on best practice. There is a need to focus on what works and in what ways practice can be adapted/transformed. Another area identified centred on research that considers the experience of professionals with respect to coming out.

Participants outlined several methodologies, which would facilitate a wider range of discussions and community involvement from the bottom-up including action research and participatory models.

The following is a list of ideas generated by participants, in no order of priority:

Building Support for GLBT-S Health Research

- ◆ Due to isolation, need meetings, web site, national clearinghouse
- ◆ Enhanced training of professionals, faculty, and students
- ◆ Schools need to include GLBT-S issues in curriculum at all levels
- ◆ Look at climate in which GLBT-S issues are discussed
- ◆ Research to look at the social relations that shape education
- ◆ Funding organizations
- ◆ Strengthen infrastructure of GLBT-S organizations (increased and consistent funding)
- ◆ CIHR needs to be involved
- ◆ Increase collaboration between communities and universities
- ◆ Publication
- ◆ Networking
- ◆ Increased multi-disciplinarity
- ◆ Enhanced mentoring
- ◆ Development of educational modules

- ◆ More partnerships between professionals and community
- ◆ Need to create a journal of GLBT-S health issues
- ◆ International meetings
- ◆ Focus on action
- ◆ Need national coordinator
- ◆ National directory of professionals
- ◆ Annual meetings
- ◆ Increased resources
- ◆ Multi-centre collaboration
- ◆ Presentation of research
- ◆ Need data for policy development
- ◆ Need common understandings between stakeholders
- ◆ Clarify roles in project development
- ◆ Lobby and educate policy makers, funders, etc.
- ◆ Challenge agenda of government
- ◆ Assert importance of GLBT-S issues
- ◆ Create discussion document(s)

Gaps in Current Research

- ◆ Focus on smaller cities, towns, rural communities
- ◆ Aging
- ◆ Experiences of professionals
- ◆ Best practices
- ◆ Involvement of young people
- ◆ Inclusion of ethno-cultural factors
- ◆ Costing for prevention/intervention
- ◆ Population health approach
- ◆ Methodologies to promote inclusion of previously excluded people, including other forms of knowledge-building in communities
- ◆ Move from AIDS to health promotion

Paper 3.

Report on Health Promotion and Outreach to Black and Caribbean Communities

Prepared by: Canadian Centre on Minority Affairs

The review of the literature and consultations with key informants in the Black and Caribbean community identified many service and information gaps that impact on the community's health. There are gaps in access to health care services, the provision of information, inclusion in health research and the carrying-out of community-specific research.

The following recommendations are based on findings from the literature review and consultation with key informants.

1. Policy Development

Participation of the Black and Caribbean community in the health care policy development process:

- a) This could involve identifying and defining policy issues, reviewing existing policies and policy evaluation.
- b) A consultative mechanism to facilitate this process

2. Capacity Building

Capacity building within Black and Caribbean organizations to enhance their ability to be effective and coordinated in helping to meet the needs of the community. Strengthened organizations would be in a better position to collaborate on initiatives to improve the health of the community. This would contribute to the sustainability of health care initiatives and require:

- a) Assistance to community sector to build effective and long-term relationships with other health care organizations
- b) Assistance in building the organizational and institutional capacity of organizations that can advocate on behalf of the community and facilitate the dissemination of health-related information

- c) Assistance in the development of the community's capacity to:
- Carry out and share research
 - Gather and distribute information to individuals and families
 - Facilitate access to expertise within the community by creating and maintaining an inventory of Black and Caribbean health care professionals
 - Design and coordinate health education for the community
 - Design culturally sensitive training for health care professionals
 - Advocate on Black and Caribbean health issues
- d) Encouraging health-related voluntary organizations to enter into partnerships with organizations in the Black and Caribbean community

3. Project Development

Provision of support and resources to assist organizations to undertake local projects that are consistent with the health priorities of the Black and Caribbean community.

4. Funding

Funding organizations to enhance their organizational capacity to advocate on behalf of the community by representing community interests and views; providing a national forum; connecting with other stakeholders and communities across Canada; and mobilizing participation and action on health within the Black and Caribbean community.

Paper 4.

Report on the Strategic Planning Workshop on Black and Caribbean Canadian Health Promotion

Prepared by: Canadian Centre on Minority Affairs

The meeting made a number of suggestions for possible collaborative and supportive action in the future. Under the general direction of the CCMA, a small working group is to take the next steps to follow up on the directions given at the meeting.

Influencing Factors on Black Health

The meeting identified the following influencing factors to the working group and any eventual mechanism that directs or influences the future direction of health care work for the Black and Caribbean Canadian population:

1. That the health system operates within the shared jurisdiction of the federal/provincial and territorial governments, and that municipalities also have a role to play;
2. That access to adequate care and good health and health promotion, and the existing chronic poor health of many in the Black and Caribbean community, is very directly a function of socio-economic status and levels of literacy;
3. That optimum health is shaped by cultural imperatives that influence the individual's interface with the health care system (how and if the person approaches health practitioners, their attitudes to the formal health care system, their ongoing follow-up to medical advice, their care of family members, and the health care system's understanding of the particular health issues, concerns, socio-economic status, literacy – both actual and medical, and cultural beliefs and attitudes, the health care system's ability to deliver appropriate care in appropriate language, and racism in allocation of funding for research and in service delivery and design);

4. That health care for the Black and Caribbean community in Canada is very much affected by what is seen as systemic racism across the sector;
5. That there are very specific health issues for women, as well as for men, and that these relate not only to specific diseases, but to culturally imposed attitudes and behaviours that affect good health;
6. That health determinants are very much amplified by the stress faced by the individual, in terms of the physical and mental violence they experience in the family and from the racism in society;
7. And that no approach to improved health care for the Black and Caribbean population in Canada can be effective without approaching it in a holistic manner that integrates all these factors, and social justice demands no other approach.

Priority issues:

The implementing actions for health were given the following priority by the meeting:

- a) Establishing a national network on Black health;
- b) Developing and influencing a national health agenda;
- c) Funding for health initiatives;
- d) Research on health issues and on the target population.

In addition, the following areas were identified as part of the overarching strategy to meeting the health care needs of the Black and Caribbean community:

1. Building a national database;
2. Building partnerships;
3. Advocacy and lobbying;
4. Establishing a think tank;
5. Monitoring and tracking of research, trends, health statistics;
6. Information/communications/education.

Toward Cultural Competence

Cultural Competence in Pediatric Health Care, Report on Proceedings of the National Workshop on Current Practices and Strategies in Pediatric Health Care

Prepared by: Children's Hospital of Eastern Ontario

Two services were most often cited in the pre-workshop questionnaire as being accessed most frequently and having the highest priority for improvement: cultural interpretation and staff education. This was reflected in the participant discussions, where they were once again felt to be the most important.

Discussion of first steps needed to develop these services, and to have cultural competence become an important agenda in health care organizations, was focused in three areas: the need for administrative and financial support, the need to build and share knowledge bases nationally, and the need to develop community links. To address the concerns the following steps were suggested for consideration:

- ◆ Initiate research within current programs and through the literature to ascertain indicators reflecting the impact of such programs on quality of care. They might include indicators of compliance, patient satisfaction, risk aversion and informed choice. Such information would provide a rationale to decision-makers.
- ◆ Position interest at senior management level. Risk management may provide an area in which to position the issue of cultural competence. Involvement of board members in the process was suggested as possibly helpful.
- ◆ Piggyback onto existing committees to create interest in cultural issues.
- ◆ Develop a series of telehealth presentations to enhance awareness of models and directions that have been taken to date. By targeting presentations to specific audiences, it can be ensured that content matches the audience. Participants could share what they have implemented or plan to implement and get feedback on challenges, barriers, outcomes and lessons learned.

- ◆ Establish a clearinghouse of resources, which would be available to all centres.
- ◆ Establish a nationwide web site for ongoing updates
- ◆ Evaluate how services address community needs. This could include community-based qualitative research and forging partnerships in the community, including the establishment of advisory committees.
- ◆ Establish closer ties with community-based non-health care agencies, such as Children's Aid Society, which have an interest in cultural issues.
- ◆ Establishing links among institutions was discussed as important to facilitate exchange of information and ensure continuance of the process of developing practice guidelines

One of the key objectives of the workshop and a top priority of participants was the establishment of linkages that would ensure ongoing communica-

tion and sharing of information. The following suggestions were made to accomplish this:

- ◆ An annual conference on cultural competence. It was suggested that such a conference could be combined with existing conferences to reduce cost and increase participation. To maximize its educational potential, the annual conference could focus on selected topics from year to year.
- ◆ The use of telehealth resources and teleconferencing to provide education and information-sharing opportunities.
- ◆ Establishment of a central resource and information clearinghouse, which would be updated regularly.
- ◆ Creation of a national phone and e-mail list.
- ◆ Establishment of a web site or inclusion of information on cultural competence on existing web sites.