

# Activity Limitations and the Need for Continuing Care: A Report on the First Nation and Inuit Health Survey<sup>©</sup>

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## INTRODUCTION

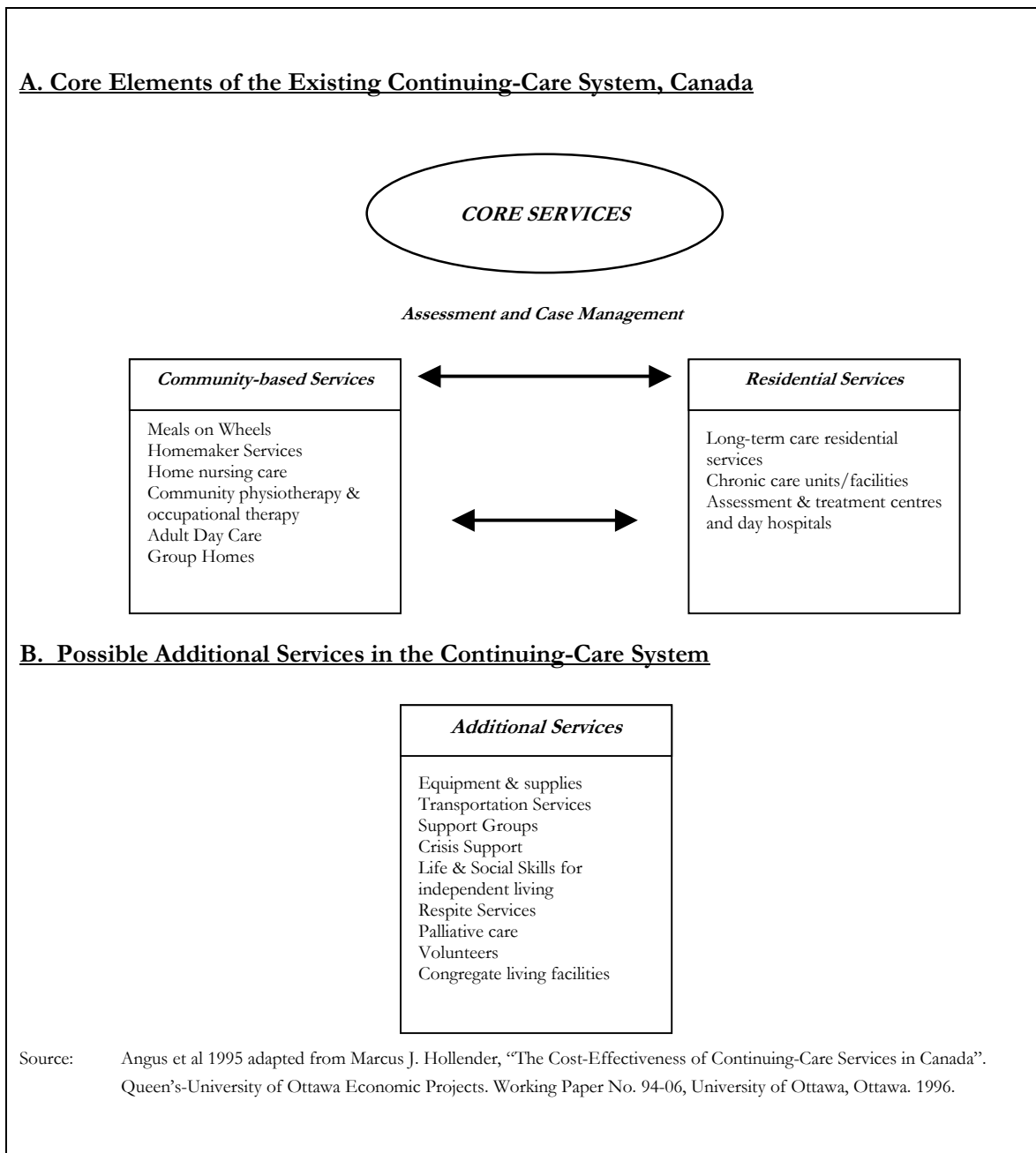
First Nations and the Labrador Inuit face a disproportionate number of serious health problems, and they are more likely than other Canadians to have a disability (Ng 1996). They are further disadvantaged because of geographic isolation and many reside in communities far from large urban centers, which provide continuing care services for people with a disability or a chronic condition (Ng et al. 1997). Although services provided by Medical Services Branch have resulted in many health improvements, health and social services for people with a disability or a chronic condition have not been forthcoming in a systematic or effective way because of intra-and inter-governmental jurisdiction problems. These problems are persistent even though a major objective of a publicly funded health care system is to provide comparable access to health services for everyone.

Health service delivery, in general, is a part of provincial/territorial programs, and it should be consistent with the Canada Health Act (1984) in that it should be accessible, comprehensive, portable, publicly administered and universal (Government of Canada 1984). Services available under this system include fee-for-service and salaried practitioners, hospital beds, and diagnostic facilities. These facilities are generally located in larger urban or rural centers. Continuing care services are provided at a provincial level, and these services vary from province to province. Two components of continuing care are that care is to continue over a long period of time and that it is an integrated program of care that continues across service components (Angus et al 1995). Continuing care services, in many ways, are an emerging system of the health sector, and as Hollender (1996) contends, in time, they will become a distinct, separate and major product line in the overall health care system.

The shape that continuing care will take for First Nation and Inuit people will be major challenge, given the complexity of the continuing care system, which varies from one provincial jurisdiction to another. For instance, continuing care services are provided to the elderly, but also serve people of all ages, including people who are mentally and physically disabled, emotionally disturbed children (e.g. FAS/FES), people with alcohol/drug problems, street youth, homeless people, single mothers/fathers, and families in crisis (Angus et al 1995).

Community-based and residential care services are an integral part of this system. Community-based services include home care, which depending on the model, targets people with health and/or functional deficits in the home setting in order to foster independent living and to prevent health and functional breakdown and even institutionalization. This care can also be long term care for people who would otherwise require institutionalization or it can be acute care for people who would otherwise have to reside in acute care facilities. Figure 1 illustrates the core elements of the existing continuing care system in Canada as of 1995 (Angus et al 1995, Hollender 1996).

FIGURE 1 – CONTINUING CARE SYSTEM IN CANADA, 1995



Continuing care is multi-faceted in that it combines aspects of health and social services into a system of service delivery (Angus et al 1995, Health and Welfare Canada 1992). The effectiveness of this system, however, largely depends on the variety of services available, the departments that deliver these services, and on the nature of the system that service delivery occurs. Effectiveness also depends on the inter-and-intra-governmental jurisdictions involved in this system of service delivery.

For First Nation and Labrador Inuit communities, there are inter-and-intra-governmental jurisdictions, which complicate the provision of continuing care. Initially, the federal Department

of Indian Affairs (DIAND) provided health services by employing part-time physicians as early as 1880 in recognition that a need for such services existed and were not being met from other sources (Department of National Health and Welfare, 1969). Health services, including health education, diagnosis, treatment, and rehabilitation, were transferred to the Department of National Health and Welfare in 1945. Indian Affairs restricted their activities to programs related to housing, education, social assistance, child welfare, policing, water, sanitation and other aspects of community health. These jurisdictions are not legislated. The Federal government interprets its provision of services and infrastructures to First Nation and Inuit people through a *1984 Memorandum of Understanding (MOU)*, which delineates responsibility between Medical Services Branch (MSB) of the Department of National Health and Welfare and the Department of Indian and Northern Development (DIAND). By way of this memorandum, all health programs are under the control of Medical Services Branch of Health Canada and most, if not all, social, education, economic and housing programs are under the jurisdiction of Indian Affairs.

Medical Services Branch (MSB) finances all community health services and environmental health and surveillance programs on-reserve, and in some areas, hospitals have been supported on a negotiated per diem by the provinces (Postl et al 1993). Community health services have ranged from disease and injury prevention, health promotion, health education, immunization, nutrition counseling, dental health, non-insured health benefits (e.g. drugs, eyeglasses, hearing aids, patient transportation), and emergency treatment where not otherwise available. MSB, for the longest time, coordinated the availability of health professionals to communities, ranging from community health representatives (CHRs) to specialist care. Community Health Representatives are front line health workers who work in the community full-time, and they have been mandated to provide disease and injury prevention programs, health promotion, health education, nutrition counseling, and interpretation. Community health nursing is also available in communities without primary care nursing stations. In communities that have nursing stations, nurses provide primary and emergency treatment, and the vast majority of on-site clinical services in northern and remote areas are provided by nurses, with physicians and specialists (psychologists, physiotherapists, etc.) providing services during scheduled visits. Larger communities have general physician services available on-site, but these communities are few. The environmental health and surveillance provided in communities involves environmental inspections, water sampling and contaminant testing. Isolated communities rely on air transport to support health services, and air ambulance support is available to these communities. Medical transportation is also available in non-isolated communities because of their distance from larger urban centers.

Federal transfer policy for First Nation and Labrador Inuit communities involves the transfer of control over these services, which adds another jurisdiction into a continuing care system of delivery. Health transfer first began in 1986, when Medical Services Branch announced the Indian Health Transfer Policy. The assumption of transfer is that community control over services will overcome some of the jurisdictional issues around health and social services.

In 1991, Medical Services Branch reviewed the health transfer process and found conflicting results. As a community development process, health transfer initiatives had helped communities establish and control health programs according to cultural, social and health needs. However, the transfer process was plagued with problems that further complicated health service delivery. Postl et al (1993) summarized some of the problems experienced. The transfer process occurred as the Federal government moved out of the administration of health and decreased its funding base for health programs. As government downsized, there was no “enrichment” policy, which meant that communities had little choice but to work within an existing but decreasing resource base. Another problem area was the lack of assurances given by the Federal government that it would not off load its fiduciary responsibility onto provincial governments. Communities had a reason to be concerned. In 1969, the federal government had considered the idea of transferring “Indian” health services

to provincial governments, while maintaining programs to contend with unmet health needs. Provincial governments, however, rejected this idea, and many continue to exclude on-reserve First Nation peoples from health and social programs because they are considered a federal responsibility.

The transfer process, which began in 1986 as a pilot project, continues with little regard for the potential impact of disabilities and chronic conditions. The limited scope of health transfer is what mainly delimits any attention to this area. The health transfer process, at the outset, excluded noninsured benefits (NIHB - MSB), social services (DIAND), and mental health services, which are critical services for people with a disability or chronic conditions. At this time, these services are under negotiation. However, the health transfer process overall may not adequately lead to the development of an effective continuing care system, which involves both aspects of health and social services. Because the potential impact of disabilities and chronic conditions on health transfer is unknown, there is no way to gauge whether the financial envelope will be adequate. There is also concern over past jurisdictional problems and their continuation. These problems create barriers to self-government, equity, and quality of life for First Nation and Labrador Inuit peoples. These barriers are further obstacles that limit the life chances of people who require the services of a continuing care system.

Health information is critical to get a sense of the continuing care needs of First Nation and Labrador Inuit peoples and the impairments that influence their need for continuing care services. To date, there is no coherent or national database on the provision of continuing care services in Canada. British Columbia, which keeps data on the major elements of its continuing care sector, have reported that the elderly are the heaviest users but younger groups also make notable use of long term facilities and community-base programs. The first wave of the First Nation and Inuit Regional Health survey provides critical and timely information, although somewhat limited, on activity limitation problems and unmet needs, which fall in the community-based area of continuing care services.

This survey is the first step towards assessing community and residential needs, including needs for additional services, of First Nation peoples and the Labrador Inuit. This paper summarizes the data from this survey and provides a profile of activity limitations and service needs. The analysis describes the population at risk and characterizes people who have limitations and unmet needs. Age, gender, living arrangements, and self-perceived health status measures distinguish people within and across these groups.

A review of the literature provides a discussion of First Nation and Inuit disability service provision issues, as well as measurement issues critical to assessing limitations. National and regional studies are also reviewed (e.g. National Health and Activity Survey 1986, Aboriginal Peoples Survey 1991, Santé Québec Survey of the Inuit and Cree 1991-2, National Population Health Survey 1994-95). These surveys, although not exhaustively examined, provide a sense of what is known about the prevalence of activity limitations and service needs and the leading causes of disability. Literature on specific chronic conditions is also reviewed to identify the activity limitations and unmet needs associated with those conditions.

The overall intent of this paper is to provide First Nations and the Labrador Inuit with information that can help shape the development and assessment of an equitable and effective continuing care system.

## 1 ADULT CARE AND DISABILITY POLICY AT THE FEDERAL LEVEL

Initiatives improving accessibility and the participation of people with disabilities have been largely due to the successful lobbying by people with disabilities themselves (DeJong 1979; Driedger 1989; Enns 1981; French 1994). National and international governing bodies have advanced several initiatives. International strategies by the United Nations have focused on disability prevention, rehabilitation, and the equalization of opportunities (United Nations 1983). *The Standard Rules on the Equalization of Opportunities for Persons with Disabilities* emphasize the rights of persons with disabilities, freedom of choice, and equal opportunities (United Nations 1993). The rules underscore the importance of adapting the environment to the individual by focusing on their abilities, not disabilities.

In Canada, several attempts have been made to develop initiatives to improve accessibility and participation of people with disabilities. However, First Nation and Inuit peoples have not had equitable access to these initiatives. The Royal Commission on Aboriginal Peoples (1995) and other national bodies have succinctly described this history of inequity.

In 1981, the Special Parliamentary Committee on the Disabled and Handicapped released their report, *Obstacles*, which called for a change in policy affecting Canadians with disabilities (Fricke 1998). In this report, the committee concluded that Aboriginal peoples live in poverty and suffer from living conditions that greatly increase the probability of being disabled at some point in their lifetime (RCAP 1995). They urged all governments in Canada to develop programs for Aboriginal peoples with disabilities. They also called for an amendment of the *Human Rights Act of Canada* to protect all Canadians with disabilities from discrimination, specifically in employment, architecture, communication systems, public transportation, and public housing areas (Enns 1981). In April 1982, the *Canadian Charter of Rights and Freedoms* was expanded to include the rights of persons with disabilities. This legislation guaranteed equal benefits and protection under the law and prohibited discrimination based on physical or mental disability (Council of Canadians with Disabilities). Provisions for enforcement or implementation guidelines, however, were not provided.

Several initiatives followed the constitutional amendment with the intent of improving the quality of life of people with disabilities. Two national surveys, which will be discussed later, were conducted by Statistics Canada to estimate the prevalence of disability. The Health and Activity Limitation Survey (1986) targeted all-Canadians, including Aboriginal people. The Aboriginal Peoples Survey (1991) targeted all Aboriginal peoples and included several questions on limitations experienced by people with disabilities. National strategies also followed the constitutional amendment.

In 1986, the Department of Health and Welfare released their report *Achieving Health for All: A Framework for Health Promotion* (Epp 1986). This report had an expanded view of health. It identified health promotion as the means to enable all people, including people with disabilities, to increase control over, and to improve their health. In 1991, the Federal government announced its first national strategy that specifically targeted people with disabilities. The national strategy called for the integration of persons with disabilities into mainstream society. This strategy applied in a limited way to First Nation peoples and the Inuit (NWI). The national program funded to a maximum of \$158 million over five years had a long list of commendable objectives to achieve, of which Indian Affairs and Medical Services Branch contributed. The Federal government interpreted this provision of services and infrastructures according to the *1984 Memorandum of Understanding (MOU)*.

Indian Affairs allocated \$5 million to improve co-ordination and accessibility and to promote sensitive design and delivery of existing social programs and services to people with disabilities living on-reserve (RCAP 1995). Health Canada responded by holding consultations to identify a

number of issues regarding health care for elderly people and First Nation peoples with disabilities on-reserve, with the promise of action to come. Medical Services Branch allocated \$2 million over five years to retrofit existing health facilities that would cost in real dollars an estimated \$7.5 million.

Other initiatives occurred, which incorporated people with disabilities into adult care services. As early as 1980, Indian Affairs established basic standards to be applied to adult care programs (DIAND 1982). However, these standards applied to basic auxiliary family services and essential home care programs. The Federal government interpreted any provision of adult care services through the 1984 Memorandum of Understanding. In Annex A of this memorandum, a definition of adult care was advanced:

*Adult care comprises a range of health and social services for adults which have, as their goal, the maximization of individual self-sufficiency through the maintenance of individual functioning and, as necessary, through encouraging the disabled and elderly to receive care within the context of the family and community. These health and social services are designed to provide assessment, treatment, rehabilitation and supportive care as well as to prevent or minimize disability of adults suffering from chronic physical, development, or emotional impairments. These services are provided to individuals, their families and their communities in a variety of health and social care settings and management.*

Annex A also listed the principal components of Adult Care and identified the responsibility of departments, Indian Affairs or Medical Services Branch, over funding and management. A qualifying statement was added which set limits on funding:

*[T]he list of components is not to be considered as either exhaustive or obligatory. The availability of these components will vary depending on the resources of the individual, the Band, and the responsible Department.*

The adult care services provided by Indian Affairs included the Home Care and Personal Care Program and funding for personal homes (some of which are jointly funded by the province). The management and administration of the Home Care and Personal Care Program fell under the “Social Services” area of Indian Affairs. This program provided homemaker services, which involved the following support services for daily living: 1) cleaning and cooking, 2) assistance with personal hygiene, 3) shopping and delivery of groceries or other goods, 4) cutting and hauling fire wood for Elders, and 5) hauling water where required. Excluded from the list were services that involved nursing care such as administration of medication or providing injections or other services requiring medical knowledge or skill. The Home Care and Personal Care Services were made available to the disabled, people with a chronic condition or who are ill, and the elderly. Access to these services could only be obtained by contacting the health office in the community or by referral from NADAP (National Alcohol Drug and Addiction Program), Child Family Services, hospital, doctor, welfare and social services, or Chief and Council.

The state of these and other continuing care services have been a national concern for some time (Health and Welfare Canada 1992). In 1989, a joint working group, comprised of MSB and DIAND staff, initially gave its support for continuing care, only to conclude that there were significant gaps in the availability of community support programs in most areas of continuing care. In 1991, Medical Services Branch recommended that a complete system for continuing care services be set up, one that would include evaluation of clients’ needs, case management, and an evaluation strategy. It was hoped that such a problem would have a mandate and the resources needed to provide home care services (Health Canada - MSB, 1991). By 1993, provincial governments were reforming their health systems, and Medical Services Branch was concerned how this reform would create a demand for continuing care services (Health Canada – MSB 1993). They were concerned with: 1) the shift to out patient services; 2) increased waiting periods for surgery; 3) increased

deinstitutionalization; 4) growth in non-insured health benefits; 5) increased demand for home nursing care; 6) the unavailability of some programs to First Nations; and 7) the lack of coordination between hospital personnel and service providers at the community level.

In August 1994, Indian Affairs and Medical Services Branch jointly funded (50-50 cost funding) an adult care needs and services assessment project for the elderly and disabled First Nation peoples (e.g. Manitoba). Medical Services Branch also received 2.5 million to support a Home Care Nursing Program. The program, like others, could only meet service needs that fell under MSB jurisdiction. The Memorandum of Understanding was used to delineate MSB jurisdiction from Indian Affairs, as illustrated in a correspondence from W.D. Rutherford, Regional Nursing Officer (MSB) to Assembly of Manitoba Chiefs (January 11, 1995 reported in the First Nations of Manitoba – Adult Care Initiative 1997):

*The funding must be used to develop a program that delivers “nursing care” and cannot be used for support of programs that are under the Indian Affairs mandate ... That is, homemakers services, attendant services and personal care are not considered to be programs to be funded from this resources base.*

This program initiative illustrates the jurisdictional ambiguity in which a continuing care system operates. It also illustrates the problems of initiatives that are developed outside of First Nations and Labrador Inuit self-governing structures. For instance, a Joint Working Group (DIAND-MSB, 1997) developed a federal strategy for the delivery of continuing care to the First Nations. Its objective was to improve access to, and the effectiveness of, home care programs to bring them into line with those delivered to the Canadian population. The working group projected that the demand for home nursing care would rise, due to the reduction in the number of hospital beds available, the shift to ambulatory care, and the early discharge of patients. The working group contended that the lack of harmonization in the availability of continuing care services offered by different departments had considerably hindered efforts to include the program into transfer, funding, and self-government agreements.

Such jurisdictional ambiguity continues, and it is a barrier to quality of care and the very essence of the Canada Health Act. The conclusion reached by a Special House of Commons committee in March 1993 still stands. There was no comprehensive plan of action then covering all Aboriginal peoples with disabilities or chronic conditions and no single agency had been charged with developing one (RCAP 1995). Today, fragmented efforts within the federal government and jurisdictional murkiness between federal and provincial/territorial governments continue to be the two main barriers to relieving unacceptable human suffering.

The federal government is now paying specific attention to a National Home Care Strategy in order to universalize access to these services (Wilkins and Park 1998). First Nations and the Inuit, however, require a national strategy formulated under Self-Government. Another Federal strategy that does not involve negotiations with First Nations and Labrador Inuit peoples, however, will complicate the development of an effective system. Provincial governments may also ignore such strategies because of federal fiduciary responsibilities. The position taken by provincial governments in delivering and financing of health and social services to First Nations people is an example of another barrier to an effective system of continuing care services.

## 1.1 PROVINCIAL BARRIERS TO CONTINUING CARE SERVICES

A great degree of fragmentation occurs when provincial governments refuse to provide services because of jurisdictional issues. For purposes of illustration, the Manitoba approach is described here. The Manitoba Home Care program first emerged to contend with the poliomyelitis epidemics of 1952 and 1953 (Desmarais et al. 1956; Alcock et al. 1984), and expanded to cover



other chronic conditions and disabilities. The Manitoba Home Care Program attempts to keep individuals with severe physical and mental health impairments in the community, especially when they do not require permanent institutionalization. It provides support and continuing care services to enable people with a disability or chronic conditions to remain in their home environment at a lower cost than institutionalization (Manitoba Health, 1992). Services provided range from nursing care (VON), orderly care for personal hygiene, homemaker services, respite care for family caregivers, meal on wheels, to rehabilitation services.

The intent of this program was not to supplement family and community networks of care in that families have to continue providing care where possible. Although considered a model for other provincial programs, it was not available to Manitoba First Nation communities because this government considered such care a federal responsibility. The 1996 policy on First Nation Government produced by Manitoba Northern Affairs Secretariat, as stated, illustrates the division over responsibility and the inaccessibility caused when federal-provincial arrangements for providing health are not in place (First Nations of Manitoba 1997):

*Under Section 91.24 of Canada's Constitution, only Parliament may exact laws in relation to First Nation peoples. Provincial legislatures have no power to enact legislation to implement special rights for First Nation people or special powers for First Nation governments (for example, child welfare on reserves)...*

*The rights of First Nation people under Treaties are constitutional rights. There are two types of Treaty rights. One is rights that First Nation people can exercise without government involvement, such as hunting and fishing. The second is other rights involving Crown promises to provide certain benefits, including reserves, schools and health care. Clearly it is the federal government that must fulfill these treaty promises...*

*Because only the federal government has special powers over the assets and affairs of First Nation people, only the federal government has the fiduciary obligations over these matters. To the extent that implementation for First Nation government will reduce these powers, it will change the relationship...*

*Manitoba will ensure that the shift of federal programs and services to First Nations does not result in further shifts of costs to the province, or pressure to fill funding gaps in services on reserves to meet provincial standards...*

*Statistics indicate that Status Indian use of health and social services is higher than that of the average Manitoban. The extraordinary costs of these services must be addressed in the federal-provincial arrangements for providing health...*

Jurisdictional posturing does little to alleviate the burden of illness experienced by First Nations and the Labrador Inuit. Instead, it contributes to the disparity that already exists. Ambiguity in the provision and funding of continuing care services consequently avoids the future development of continuing care services and creates further disparity.

## **1.2 DISPARITY, PROGRAMS, AND NEEDS**

High levels of poverty experienced by First Nations and the Labrador Inuit have strongly influenced epidemic levels of certain chronic and acute conditions over time and have limited their life chances (Young 1994a, 1994b). The following discussion illustrates that programs currently available are not funded by levels of disparity or need, which is problematic given the high rates of disabilities and chronic conditions experienced by this population. As impairment advances, it can be hypothesized that more extensive use of services will be required such as rehabilitative services, assistive devices (helping aids), and barrier free and healthy environments (private dwellings and

public buildings).

For instance, a rehabilitation team, in an ideal sense, is composed of physiotherapists, occupational therapists and speech language pathologists, working in conjunction with physicians, nurses, psychologists, social workers, dieticians and other health care providers as required. Together, they are to work with the client to pursue interventions that assist the individual's return to as active and independent lifestyle as possible. However, there is much disparity in how these resources are distributed, given the high rates of disability reported by First Nation and Labrador Inuit peoples. When rehabilitative services are available, they are limited in quantity and in the type of service offered. For extensive services like vocational rehabilitative services, individuals must leave their communities and establish a permanent residence in a larger urban or rural center. The same applies for extensive rehabilitation after a stroke, limb amputation, or joint replacement. Individuals, requiring these services, are referred to urban settings, resulting in relocation away from the support provided by family, friends, and community. When they return, they must depend on the support of their family, friends, and nursing personnel who may have inadequate resources to provide support.

Continuing care services available through the Non-Insured Health Benefits Program (NIHB) provide supplementary health benefits to over 650,000 registered Indians, Inuit and Innu peoples to meet medical or dental needs which cannot be met by provincial services or other health plans. This purpose of this program theoretically is to provide benefits that are appropriate to "unique health needs" and to contribute to an overall health status that is comparable to the all-Canadian population. The program has to sustain a fiscal and benefit management perspective, yet facilitate First Nations and Inuit control at a time and pace of their choosing (Health Canada 1997). Under this program, assistive devices for people with disabilities and chronic conditions are made available to enhance independence. They may be used for functional activities, such as mobility or agility; pain management, such as resting splints for inflamed joints or prescription drugs; or prevention of further deterioration. Other items include eyeglasses and hearing aids, limb braces, wheel chairs, crutches, or augmentative communication devices. Historically, this program has been plagued by administrative inconsistencies, which resulted in the inconsistent availability of services (Waldram et al 1995).

To access specialist services that provide devices and other medically required services, many First Nation and Labrador Inuit people have to depend on the medical transportation system currently available under NIHB program. However, if a community has a fixed transportation budget and high service needs, some individuals may have to wait until their condition becomes so chronic that they have to be sent out resulting in a cost over run in the transportation budget and a more complicated condition to treat. Transportation funding is not the only barrier experienced. For some people, it can be barrier if attendants (DIAND) are not provided or if the transportation system itself does not meet accessibility standards. For instance, public transportation to remote northern communities is only possible by airplane. The accessibility guidelines for people with disabilities in the *Air Transportation Regulations* (Transportation Canada 1991; National Transportation Agency of Canada 1994) apply only to carriers with more than 30 seats. The aircraft generally used to provide scheduled service to many remote communities have less than 30 seats, which means that these transportation companies are not required to meet the same accessibility standards. Other transportation limitations can occur. In many communities, local governments or private companies that provide taxi service do not offer accessible transportation for medically required services as found in urban settings, such as wheelchair accessible vans.

Other problem areas involve environmental barriers, such as housing or public building barriers that prevent someone with a disability or chronic condition from using these environments to their full capacity. In most cases, Indian Affairs has jurisdiction over public infrastructures except for public health buildings, which fall under the jurisdiction of Medical Services Branch. Public

buildings, in general, can vary in terms of their universal accessibility. Communities have been encouraged to consider access issues in the construction of any new public buildings by the federal government. Many buildings, however, remain accessible to only a selected portion of the population because funding is limited and there is no enforcement of accessibility regulations (Fricke 1998).

Housing conditions are another potential barrier, which is under the jurisdiction of Indian Affairs. Limited housing resources in First Nation and Labrador Inuit communities have been an ongoing concern and may contribute to high rates of disability and chronic conditions. In Table 1, some probable relationships between housing conditions and health have been identified (adapted from the Canadian Medical Association 1994).

TABLE 1 – HOUSING CONDITIONS AND HEALTH PROBLEMS

Housing Conditions	Health Problems
Crowded Conditions	Infections (e.g. respiratory, skin and eyes, tuberculosis, meningitis, measles) Injuries Mental Health Homicides and domestic/non-domestic violence
Inadequate housing stock (e.g. houses in disrepair)	Injuries
Water and sewage systems	Gastroenteritis Skin Infections
Indoor Air Quality (e.g. wood stoves, high humidity levels and mold, cigarette smoke)	Respiratory Symptoms (e.g. Asthma)
Cleanliness (dust)	Respiratory (e.g. Asthma)
Structure: 1) steps and hand rails; 2) cupboards and closets; 3) washrooms; 4) exterior doorway; and 5) interior doorways.	Barriers for people with a mobility, agility, sensory or physical disability
Safety: 1) no electricity or appliances resulting in candle, kerosene lamp, or camp stove use in the home; 2) faulty wiring; 3) faulty installation of wood stoves; 4) no inspection or cleaning of chimneys in houses with wood stoves.	Fires

Overcrowding and safety issues are major concerns reported by First Nation peoples living On-reserve (Statistics Canada 1994). Historically, household crowding had characterized the poverty of First Nations and the Labrador Inuit. It continues to be a major problem as the supply of housing fails to accommodate a fast growing population. Although the average Canadian home had 0.4 persons per room (Statistics Canada, 1994), overcrowding was twice the national rate for Inuit and on-reserve dwellings in 1991, with an average of 0.8 persons per room. While significant efforts have been to rectify this situation, the demand for adequate housing is still high. Because of this demand, decision-makers are forced to consider the housing needs of not only the individual with impairments but of all community members. For instance, special housing for a disabled person in a wheelchair may conflict with community development priorities that are limited by funding. As a result, individuals with a disability have to rely upon the good will and intentions of their elected

officials, as long as accessibility policies regarding adequate housing are not funded or enforced adequately.

The Home Care and Personal Care Program (DIAND) and the Home Care Nursing Program (MSB) continue to be offered. Most First Nation communities provide housekeeping and home help services through their band or tribal councils, and trained medical staff will make home visits but often these visits are not a priority when there is a large clinical workload. Supplementary services are rarely available such as personal care services, meals on wheels programs, and volunteer services. Almost all regions have acknowledged major delays in case management, as well as problems regarding the evaluation of clients' needs. Current alternatives to institutional care, like residential homes for the elderly, adult day care, family home care, and integrated home and institutional care services, are not offered or are inaccessible to the vast majority of First Nations and Labrador Inuit. In addition, existing funding levels are inadequate and generate further inequalities and much criticism.

### 1.3 CRITICISM OF FEDERAL INITIATIVES AND PROGRAMS

Overall, Federal initiatives and programs have not addressed the major problems experienced by First Nations and the Labrador Inuit. Inadequate programs continue to create frustration and to foster much criticism. The following reports provide a sense of the frustration experienced by First Nation people.

The *Obstacles* and the *Follow - Up Report: Native Population* (Special Committee on the Disabled and the Handicapped 1981 and 1982) first identified the major problems experienced by Aboriginal people in general. *Completing the Circle* (Standing Committee on Human Rights and the Status of Disabled Persons 1993) and *The Path to Healing* (Sinclair 1993) illustrated the continuing history of inequity, as did other reports. Each report consistently identified the major determinants to poor health 1) jurisdictional problems in health and social service delivery, 2) unemployment, 3) poverty, 4) social-geographic isolation, and 5) inadequate living conditions. They also addressed such issues as disability prevention, coordinated service delivery, accountability, and accessible/culturally sensitive health care. Similar issues were identified by the Council of Canadians with Disabilities (Demas - *Native Consumers Speak Out* 1987; *Access to the Sweet Grass Trail* 1993).

The *Report on B.C. Aboriginal People with Disabilities* (1993) also identified a need for equal recognition by all governments, including First Nations. This report also identified poor economic conditions, high unemployment, attitudinal barriers, and inaccessible, culturally inappropriate service delivery issues. They also identified inadequate living conditions, and emphasized as their first priority the need for affordable and appropriate housing.

In the *National Strategy for the Integration of Persons with Disabilities Report: National Consultation on Continuing Care Needs in First Nation Communities* (Health Canada, 1994), continuing care services on-reserve were compared to their provincial off-reserve counterparts. Existing services on-reserve were criticized for under funding, and an overall lack of integrated programming. The discontinuity in care was magnified by an absence of formally trained personal care attendants, case coordinators, dedicated Home Care nursing staff, and standardized measurement tools to assess the support required.

In summary, these reports illustrate that program and special funding initiatives have not fully addressed poverty, inadequate housing, poor education, inadequate social support, mobility limitations, and fragmented health service delivery that were first identified in 1981.

#### 1.4 MEASURING FUNCTIONAL STATUS, RESOURCE NEEDS & DISABILITY

Ideally, population based estimates should provide comprehensive measures that document activity limitations and resource needs by measures that differentiate *impairment*, *disability*, and *handicap*. These dimensions have evolved from initiatives to standardize the measurement of disability by the World Health Organization (WHO). In 1980, the WHO published the *International Classification of Impairments, Disabilities and Handicaps*, which added a functional component to the condition specific morbidity categories of the *International Classification of Diseases* (World Health Organization 1980).

*Impairments* represent mobility, sensory and intellectual or “deficits” or abnormalities of psychological, physiological or anatomical structure or function. In much of the literature impairments are actually measured as consequences of specific diseases or less specific dysfunction or anomalies of organ systems. In the epidemiological and clinical literature, impairments are measured as observed signs of pathology, injury or congenital malformations (Verbrugge 1990). *Disability* is a measure of difficulty in performing an activity in a manner or within the range considered normal for human beings. The concept thus refers to the consequences that impairment or “health problems” present for a person doing activities at home or in a community environment. In this context, disability is disability experienced by the person as a whole (Verbrugge 1990). *Handicap* refers to disadvantages experienced by a given individual, resulting from an impairment or disability that limits or prevents the performance of a social role or that creates barriers in the physical or social environment. Social role performance is defined in terms of the age, gender, social and cultural context within which the individual functions.

These dimensions have been proposed as a mechanism for making distinctions between the physical, sensory measures of impairment, social role performance (reflected in activity limitations), and handicapping effects of physical and social barriers which become obstacles to participation in home and community environments (Woods 1987). These dimensions have undergone continuing re-examination at both the conceptual and operational level. There has been much discussion as to how activity limitations and the need for compensating resources has been approached in the published data on functional status and in the estimates of disability-related service needs of First Nations and the Labrador Inuit.

Measures of the prevalence of disability among Aboriginal peoples in Canada have applied some elements of this more comprehensive approach by including questions that document impairments or losses/deficits in physiological, psychological or anatomical losses or deficits in function or structure. In 1986, the National Health and Activity Limitation Survey (HALS) and the Aboriginal Peoples Survey (1991) included questions that documented morbidity associated with the incidence of specific chronic illnesses. Impairment related to specific chronic conditions has already been described in Young’s et al (1998) report on chronic illness. Young’s analysis of the Regional Health Survey data shows that individuals who report significant chronic illnesses include disproportional numbers of individuals who also report activity limitations.

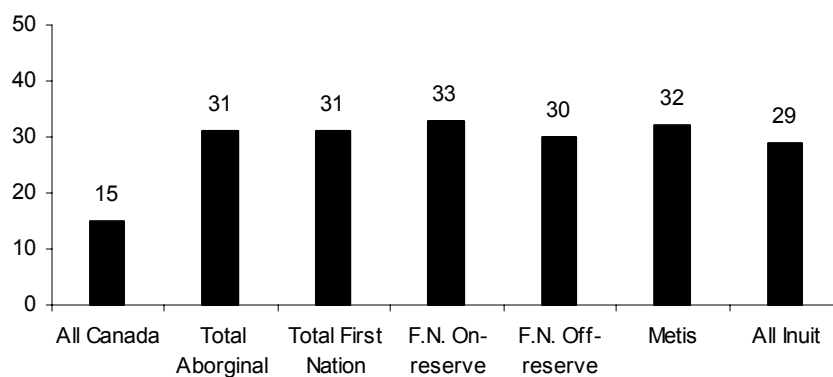
Most surveys include questions that measure disability in terms of the effects of impairment on functional status. The HALS and APS also included questions that measured a selected inventory of activities of daily living and “instrumental activities” reflecting peoples functional independence at home and in the community. These surveys also included partial measures of handicap or disadvantage resulting from environmental, social, or psychological barriers limiting the function of persons with disabilities. Other questions included in the HALS and APS involved housing quality, mobility within the home and community, and transportation access, which all indirectly document barriers to functional performance.

## 1.5 PREVALENCE OF DISABILITY AND ADULT CARE NEEDS

In 1986, the Canadian Health and Activity Limitation Survey (HALS) had estimated that 10% of First Nation peoples living on-reserve and that 13% living off-reserve experienced some type of disability. The National Aboriginal Network on Disability (1990) criticized these findings as an underestimate of the true rate of disability among Canada's Aboriginal peoples. They outlined the following reasons for the underestimation: 1) the survey excluded Aboriginal peoples living in institutions; 2) some communities refused to participate in the survey; 3) survey questions were inconsistent with cultural interpretations of "disability;" and finally 4) the length and complexity of the research tool limited participation.

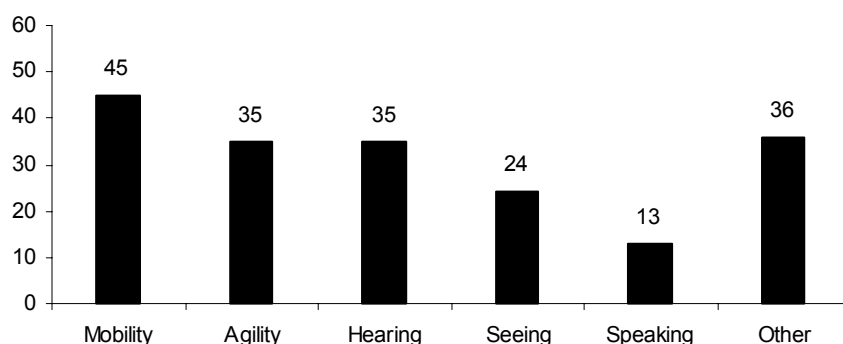
In 1991, the *Aboriginal Peoples Survey* (APS) was the first attempt at a national post census survey, which targeted persons in the 1991 Census who reported Aboriginal origins or registration under the Indian Act of Canada. From this population, individuals were randomly selected and interviewed. The overall response rate was 78.5% (Statistics Canada, 1993b). The survey included a number of questions on functional limitations. From this survey, it was estimated that nearly a third of all-Aboriginal peoples (31%) aged 15 years and older had a disability (Figure 2). This rate was more than double the national rate for that time period (Statistics Canada, 1994). For the age group 15 to 34, the disability rate was three times higher for all-Aboriginal peoples than for all-Canadians, 23% and 8% respectively. There was little difference between the Aboriginal groups. However, the disability rate of all-First Nations People living on-reserve (33%) and all-Inuit peoples (29%) was high.

FIGURE 2 – DISABILITY RATES, COMPARING ALL ABORIGINAL PEOPLES TO THE ALL-CANADIAN POPULATION (STATISTICS CANADA 1994) %



According to Statistics Canada (1994), mobility was the most common type of disability reported by Aboriginal peoples with disabilities (45%), which was comparative to all-Canadians (Figure 3). Agility was the second most commonly reported disability (35%), followed by hearing (35%), and seeing (24%). Differences in the nature of disability also existed between Aboriginal groups. Mobility was the most common type of limitation reported by First Nations and Métis, followed by agility. In comparison, hearing impairments were the most frequently reported type of disability by the Inuit (44%), while ranking only third (35%) among First Nation Peoples (Statistics Canada 1994). These rates are almost double those reported by the rest of Canadians. The higher incidence of hearing loss among Aboriginal peoples had often been attributed to a higher incidence of repeated middle ear infections (otitis media), environmental factors such as increased noise exposure, and a lack of readily available health services in remote northern communities.

FIGURE 3 – TYPES OF FUNCTIONAL LIMITATIONS EXPERIENCED BY ABORIGINAL PEOPLES (STATISTICS CANADA, 1994) %



- Mobility:* Limited in the ability to walk, move from room to room, carry an object for 10 meters, or stand for long periods.
- Agility:* Limited in the ability to bend, dress or undress oneself, get in and out of bed, cut toe-nails, use fingers to grasp or handle objects, reach or cut one’s own food.
- Seeing:* Limited in the ability to see a printed page or to see someone from four meters, even when wearing corrective glasses.
- Hearing:* Limited in the ability to hear what is being said in a conversation with one or more people, even when wearing a hearing aid.
- Speaking:* Limited in the ability to be understood when talking.
- Other:* Limited because of a learning disability or because of a mental health condition.

Nearly a quarter (24%) of Aboriginal peoples reporting a disability indicated that they used specialized technical aids or services (Statistics Canada, 1994). Technical aids were used for the management of visual impairments (74%), followed by mobility or agility impairments (33%), and hearing impairments (16%).

The proportion of individuals who reported a need for assistance in completing their activities of daily living are presented in Table 2 (Statistics Canada, 1994). Reported activities include personal care, light housekeeping, and meal preparation. These activities are normally included in the services provided by a provincial continuing care program. Of note is the high reliance on family members for assistance. The survey did not explore the impact, if any, that these dependency relationships had upon either the individual or on family members.

TABLE 2- SUPPORT NEEDS AND SOURCES OF SUPPORT

	Personal Care	Light Housekeeping	Meal Preparation
% People needing help	5%	17%	7%
% People getting help	91%	88%	95%
% Receiving Help from their family	75%	84%	84%
% Receiving help from external sources (excluding help from friends & neighbors)	35%	25%	27%

The need for assistance when travelling was also high. Almost 10% of people reported difficulty taking short trips, of which 29% were unable to leave their residence, and 13% needed a companion or attendant on short trips (Statistics Canada, 1994).

The Santé Québec Health Survey (Québecers 1987; Cree 1991; and Inuit 1992) assessed disability as short-and-long-term by leading cause. In this survey, short-term disability was defined as generally affecting people who were usually in good health and involved younger age groups forced to reduce or curtail activities for a certain period of time. Long-term disability was defined as exerting a limiting affect on overall activities and hampered individuals mobility and capacity to function independently. This form of disability characterized the elderly population. Tables 3 and 4 illustrates the leading causes of short-and-long-term disability among the Inuit, the Cree and Québecers. Short-term disability for the Inuit and Cree is primarily associated with respiratory and other illnesses, whereas a larger proportion of short-term disability for Québecers is associated with osteo-articular problems and accidents. Long-term disability for all groups is primarily associated with osteo-articular problems, but Cree and Québecers have a larger proportion associated with circulatory disease.

TABLE 3 – LEADING CAUSE OF SHORT-TERM DISABILITY, SANTÉ QUÉBEC SURVEY

Short-term Disability Leading Causes	Population		
	Inuit	Cree	Québecers
Respiratory	41	30	27
Other	20	22	18
Digestive	15	4	11
Discomfort/Headache	7	13	7
Osteo-articular	7	9	12
Lesions/Accidents	6	8	10
Skin infection	3	1	1
Circulatory problems	1	3	6
Sense-organ problems	-	10	3
Pregnancy & genital problems	-	1	2
Mental Problems	-	-	3



TABLE 4 – LEADING CAUSE OF LONG-TERM DISABILITY, SANTÉ QUÉBEC SURVEY

Long-term Disability Leading Causes	Population		
	Inuit	Cree	Québecers
Osteo-articular	36	25	27
Discomfort/headache	9	-	-
Sense-organ problems	9	1	3
Digestive	4	2	2
Circulatory	4	13	16
Skin infection	4	-	-
Metabolic and endocrinal disease	4	1	2
Mental problems	3	7	5
Lesion/accident	Not Asked	10	11
Respiratory	-	13	5
Other	26	28	25

Limitations have been associated with having at least one chronic condition in the Canadian population. In the National Population Health Survey (1994-95), the majority (75%) of people aged 55 and over who live in the community, as opposed to living in long-term health care institutions, reported that they have at least one chronic condition (Wilkins and Park 1996). Overall, about one in six people over 55 reported some physical limitations. Gender differences were apparent. One in six men and one in four women needed help with everyday activities such as housework or meal preparation. With advancing age, it was found that the prevalence of most chronic conditions increased, as did the prevalence of physical problems and dependency. The conditions most strongly related to physical limitations and the need for help were epilepsy and the effects of stroke. In the 55 and older age group, arthritis/rheumatism, non-arthritis back problems and cataracts were all associated with physical limitations and dependency.

Successful prevention and postponement of functional disabilities depends on early diagnosis of illness and on identifying even minor signs and symptoms of disease and functional limitations (Laukkanen et al. 1997). As a result, there is a need to focus health care interventions accordingly. In general, functional status measures of the individual are not linked to the presence or absence of specific diseases and their diagnostic labels, which is critical to understand impairment and functional status (Young 1998). Although the relation between poverty and poor health is well established, there are also limited studies that link the cumulative impact of social-economic conditions to chronic conditions and functional limitations (Lynch et al. 1997).

## 1.6 BURDEN OF ILLNESS AND ITS LINK TO LIMITATIONS

The disparity in rates of injury, accidents, violence, self-destructive/suicidal behavior, and chronic illnesses all correspond with the disparity between First Nation/Inuit rates of disability and that of the Canadian population (RCAP 1995). The magnitude of illness experienced by First Nation and Inuit peoples has been well documented (Mao et al. 1986, Morrison et al. 1986, Young 1988,

1990, 1994a, 1994b, 1998, O'Neil 1995).

Although disease rates are higher than Canadians, there are some noteworthy differences between Inuit and First Nation peoples (Bjerregaard and Young 1998). Circulatory diseases are more prevalent in the First Nation population than the Inuit population. The apparent low risk of heart disease (e.g., ischemic) in Inuit people is associated with their country food (fish and sea mammals) dietary habits, which includes fatty acids (high HDL and low LDL) that are heart healthy. Other diseases, such as respiratory conditions and diabetes, also distinguish First Nation peoples from the Inuit. The Inuit, historically, have had higher rates of respiratory morbidities (e.g., T.B. and chronic lung diseases) than First Nation people, but smoking has attributed to higher rates in both populations. However, First Nation people continue to have higher rates of diabetes and diabetes co-morbidity than the Inuit, but the rates for the Inuit are rising with the shift to low quality store bought foods.

First Nation and Inuit peoples also have higher hospital admission rates and increased morbidity patterns overall. For instance, hospitalization data for the provinces of Saskatchewan, Manitoba and British Columbia reveal that hospitalization rates are higher among on-reserve First Nation people for most causes than the provincial population, with the exception of neoplasms. In Manitoba, the age-standardized hospitalization rate for infectious diseases, circulatory diseases, respiratory diseases, and injuries were 6.3, 1.8, 3.0, and 3.3 times higher among First Nation people than other Manitoba residents (Young 1994b). They also tended to visit physicians more often for respiratory and endocrine-nutritional-metabolic diseases.

The evidence suggests that a number of specific chronic conditions have had a significant influence on the high disability rate amongst First Nation and Inuit peoples. Poverty or acculturation has been driving the burden of illness experienced by Aboriginal peoples (Bjerragaard and Young 1998). Older people generally have more chronic health conditions such as diabetes (Type II), cardiovascular problems and arthritis (i.e., rheumatoid and/or osteo-arthritis). They also report respiratory problems, but as a single morbidity, this problem is more prevalent in younger populations.

Diabetes, which is at epidemic levels in First Nation communities, is a major illness that causes medical complications and activity limitations due to disability (Young 1994a; also see Mueller et al. 1997). Kidney disease, heart and circulatory disease, blindness, amputations, nervous system disease, and birth defects among infants born to diabetic mothers are complications and disabilities experienced by diabetic First Nation peoples and to a less extent by Inuit peoples. The development of non-insulin diabetes is not a condition that only characterizes adults but occurs in adolescents and it can be a debilitating condition, which requires support to deal with the disease (Burroughs et al. 1997).

Activity limitations can also occur from a number of cardiovascular diseases. Shortness of breath (angina), leg pain (peripheral vascular disease), tiredness/weakness (murmurs), and dizziness/fainting (arrhythmias) can affect mobility in the home and force some individuals to be house bound or unable to travel long distance. Cardiovascular disease is also associated with sleep disturbances that limit activities of daily living (Newman et al. 1997).

Arthritis is another major health condition experienced by First Nation and Inuit peoples, and this disease results in lifelong disability from joint deterioration regardless of age resulting in the need for support around the home or with personal care. Most cases of arthritis are osteo-arthritis, and prevalence rates do increase with age. It is the leading chronic condition in mid and late life, and women's rates exceed men's at all ages (Vergrugge 1995). Higher rates in later life for women are associated with menopause. It is the leading causes of disability and limitations in activities of

daily living, and its economic, psychological and social impact are enormous (Callahan et al. 1996). Women with this condition are more likely to report poor to fair health, as well as a physician diagnosis of angina, myocardial infarction, hypertension, diabetes, stroke, lung disease, and hearing and vision problems (Hochberg 1995). For all age groups and across gender, arthritis and other musculoskeletal disorders are the leading chronic condition, resulting in long-term disability, restricted activity days, and high health care utilization (Bradley et al. 1994).

Respiratory conditions, such as chronic obstructive pulmonary diseases (COPD), can result in activity limitations (Miles-Tapping 1994). COPD is a group of diseases (emphysema, chronic bronchitis, bronchial asthma, cystic fibrosis and bronchiectasis) characterized by increased resistance to flow in the airways of the lungs, usually resulting in variable degrees of dyspnea, rapid tiring, wheezing and cough productive of sputum. Decreased lung function that can disturb night rest, limit home activity, stop people from going outdoors (especially during cold weather), restricting their ability to leave home or to go on trips, personal care (feeding and dressing), or walking and talking due to shortness of breath. Such conditions are often associated with cardiovascular conditions (e.g. right heart failure), which create further impairment.

Co-morbidities can also increase the degree of functional limitations and the support required, especially in specific cultural groups characterized by low social-economic status (Haan and Weldon 1996). Diabetes and some cardiovascular conditions (hypertension and myocardial infarction heart disease) can result in blurred vision, which can affect functioning and wellbeing (Lee 1997). Difficulties escalate for people with arthritis when they have other concurrent conditions (Verbrugge et al. 1991). Arthritis and cardiovascular diseases are associated with functional limitations (Boult et al. 1994). When individuals have complex co-morbidity, the increased likelihood that they will require intensive support or will experience activity limitations (Brod 1998; Perkowski et al. 1998) or institutionalization may increase (Culler et al. 1998; Wolinsky 1997, 1998; Miller et al. 1996). For young people, the development of chronic conditions early results in restricted activity days and greater need of support, much like the experiences of childhood disability that have a profound impact on them, the education system, and the health care system (Newacheck and Halfon 1998).

People with mental health problems (e.g. depression) also have substantial and long-lasting functional limitations that are equal or exceed people with chronic medical illnesses (Hays et al. 1995). Hearing impairment is another type of disability. Along with excessive noise (Moffatt et al. 1994), otitis media has resulted in a lifelong hearing disability among First Nation and Inuit people (Duval et al. 1994). Otitis media is an acute or chronic inflammation of the middle ear due to an infection caused by a cold or flu and often results in premature hearing loss in children and life long hearing loss (Woods et al. 1994). This condition consequently requires the need of specialist care (audiologist and ear, nose and throat specialist) and of hearing aids early or later in life if medical and surgical management (Tympanoplasty) is not successful.

Overall, the high prevalence of chronic morbidities are a cause for concern for First Nations and the Labrador Inuit, especially if the continuing care system and funding environment does not adequately meet their needs.

## 2 SUBJECTS AND METHODS

### 2.1 PARTICIPANTS

The First Nations and Inuit Regional Health Survey was conducted in 1997 in nine regions of Canada: British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec (excluding James Bay Cree and Inuit), New Brunswick, Nova Scotia, and the Inuit communities of Labrador. Each region designed their own survey questions. In addition, a limited set of national core questions were replicated in each regional survey. The final sample population was 9870, of which 5782 were women and 4040 were men aged 15 and over. The sample was weighted to represent the national population of on-reserve people and Labrador Inuit. A population expansion weight, derived from the age and sex strata of each regional target population, was calculated to provide prevalence estimates for the national target population. The survey represents approximately 199,782 people, of whom 98,269 are women and 101,513 are men.

### 2.2 MEASURES

Activity limitation questions used in the First Nation and Inuit Regional Health Survey did not measure comprehensive functional status, differentiating impairment, disability and handicap. The questions also do not facilitate more specific determination of whether activity limitations reflect the direct effect of physical, sensory or developmental impairments. In addition, it is not possible to determine directly whether activity limitations reflect the presence of physical or mental impairments or the impact of “handicapping” factors in the social environment (e.g. caring responsibilities for children or elders limiting mobility and role performance). It is also not possible to determine whether they are the impact of physical environmental barriers (uneven terrain, inaccessible buildings) or the need for services or resources facilitating rehabilitation, mobility, and functional independence. The limitations in the range of functional indices and the lack of questions probing sensory impairment, means that data from the First Nations and Inuit Regional Health Survey cannot generate estimates of the incidence of all dimensions of disability. The analysis also cannot generate comparable estimates generated in major epidemiological studies of prevalence within defined populations.

The decision was made to include only a limited number of questions dealing with individual functional limitations and need for compensating services. The intent of these questions was to provide policy relevant indicators of unmet need. The strength of this approach is that it provides basic information on the impact of impairment on mobility and self-care capacity. It also provides information on the perceived needs for assistance for activities of daily living and mobility. In general, questions reflected community requirements for pragmatic measures of individual, community and regional estimates of the incidence of functional limitations influencing self-care and mobility. Questions asked also provided immediate measures of the need for compensating services, environmental adaptations and mobility assistance. Overall, data was required that had immediate relevance to ongoing initiatives, which require an estimate of a generalized need for services especially for negotiations around health transfer service agreements and for the estimation of home care.

Several questions were adopted from the Aboriginal Peoples Survey, which documented activity limitations and perceived need for compensating services. These questions probed whether in the home environment a person experienced limitations because of a long-term physical condition or health problem, which continued over a 6 months period. Need for compensating care for functional limitations to enhance performance of key self-care activities was measured by asking: *Because of your condition or health problem, do you need help with your personal care, such as washing, grooming, dressing and feeding yourself?* A follow-up question probed the extent to which a limited array of self-care functions were provided and asked if the individual needed more help. This question, however, was not

included in the analysis because of the differences in way the question was administered in different regions.

Three questions addressed mobility limitations. One question probed mobility limitations over distances: *Have difficulty leaving your residence to take short trips, that is trips to work, shopping, or any other local trips under 80km or 50 miles?* Another question probed the extent to which individuals were unable to leave their homes: *Consider yourself house-bound, that is unable to leave your home?* The third question asked whether people *“Require an attendant or companion to accompany you on short trips.”* There was also a single question dealing with sensory impairment and asked: *“Do you have any difficulty hearing what is said when you are having a conversation with one other person?”* A more complete set of items documenting other sensory and intellectual impairments was not included in this survey.

A dichotomous “limitation” variable was created from the activity limitation and need for support questions. An index was created by summing the responses of the questions and then collapsed to identify people with limitations and people with no limitations. The sensory impairment question was not included in this calculation because it represents a limitation that is uniquely attributable to a medical device intervention, which needed to be assessed independently. To characterize the population experiencing limitations and the population at risk, several measures were derived: age, living arrangements, self-reported health status, and chronic condition measures.

Age was grouped according to time frames along a life cycle, which also represent the cumulative history of life experiences and morbidity development (Arber and Ginn 1993). The age group 15 to 29 years of age represents a group that is less likely to experience chronic conditions and should be largely free of limitations, with the following exceptions. Some young people have a disabling condition from birth. Some develop a condition early, or may have an injury disability. The experience of poverty may not be as great in this group, but for some it may be more apparent. The age group ‘30 and 54 years’ is a period when chronic conditions and co-morbidity appear early, resulting in a need for support or restricted activities. The greatest need for adult care and the most activity limitations generally occur in the 55 years and older group (Wilkins and Park, 1996). It is a period in which the cumulative history of living in poverty manifests itself as complex co-morbidity.

Education (less than high school and high school +) was used in a descriptive way. It is intricately tied to age (Young et al. 1998). It also reflects the social-economic mobility of people. People with low education, especially in the middle and older age groups, are far more likely to have experienced poor social-economic status for most of their lives and are more likely to continue experiencing poor social-economic status. As a consequence, this variable was used to reflect the extent of poverty experienced by First Nations and the Labrador Inuit. Since the age and education variables were intricately intertwined however, age was used for more in depth analysis.

If living arrangements play a major role, one would expect to find that people who live with a partner would have lower morbidity and activity limitations/need for support than people who would live alone (Joung et al. 1994). This measure is a proxy measure of the social support in the household. It is also a measure of the stress in a household if the household is dependent upon limited resources, is overcrowded, or the house itself is in need of repair. These measures illustrate the persistent link between poor social-economic position and physical demands to which persons of lower social-economic position are exposed (Kaplan et al. 1986). However, no information was collected at the level of the individual on these dimensions and the community level data on crowding and housing stock may not adequately reflect all the dimensions of these potential stresses. The living arrangement measure was derived from the marital status of respondents and whether children under eighteen were living in the house. The dimensions of this variable covered single people without children, single people with children residing in the household, respondents with a partner and no children living at home, and respondents with a partner and children residing in

the household. Although this variable has potential as a proxy measure of social support, caution has to be exercised in its interpretation as support. The survey only asked questions on the respondent's marital status and whether children under the age of 18 years were currently residing in the household. This variable, consequently, does not include other adults living in the house or their relationship to the respondent. The interpretation of this variable in relation to the support or stress that living arrangements can create is therefore limited to a nuclear family composition opposed to an extended family system. The extended family system, which characterizes many First Nation and Labrador Inuit communities, may reflect support available but a shortage of housing often results in extended family members residing in family member's homes which may contribute to further stress in the household.

An overall measure of health conditions was constructed to distinguish people with no chronic conditions from people with at least one chronic condition. Several co-morbidity variables were constructed. A diabetes co-morbidity variable was derived to identify people with only diabetes, people with diabetes and high blood pressure, people with diabetes and heart problems and people with diabetes, high blood pressure, and heart problems. A co-morbidity variable for arthritis was also constructed. It identified people with arthritis only, arthritis and diabetes, and arthritis, diabetes and a cardiovascular condition. A respiratory co-morbidity variable was constructed. It identified people with respiratory conditions only, respiratory and cardiovascular conditions, and respiratory, cardiovascular and arthritis conditions. Another measure of health used was self-perceived health status, and it identified people with poor to fair health and very good to excellent health.

In the analysis, several ecological variables were used, and they identified respondents who shared a particular group characteristic. The variable "isolation from health services" and the variable "health transfer status" describe shared group characteristics, and they were derived from Medical Services Branch community level data. The measure "isolation" describes if people come from a community isolated from health services or not isolated from health services. The "health transfer measure" represents individuals who live in communities that have entered pre-transfer agreements, signed health transfer agreements, or have not entered into health transfer negotiations. These ecological characteristics were attached to each individual in the First Nation and Inuit Regional Health Survey through their community of residence. Previous studies have used similar types of ecological measures, and consider them valid measures of group characteristic that can be associated with various outcomes (Haan et al. 1986; Dougherty et al. 1990; Krieger 1992; Kaplan 1996; Kaplan et al. 1996). These measures are sometimes used as proxy measure when individual measures are not available.

Other proxy measures were used to describe the level of disadvantage experienced at the community level. Infrastructure measures, such as housing adequacy, crowding, and adequacy of water and sewer services are associated with poverty experienced by First Nations and the Labrador Inuit. Similar measures have been used in recent population health studies that have examined the social-economic determinants of health (Kaplan 1996, Kaplan et al. 1996, and Krieger 1992). For descriptive purposes, other ecological measures characterize disadvantages in the social environment. They are population size, crowded housing (<4 people or 4 or more people), housing stock (less than 50% are inadequate or 50% plus are inadequate), water and sewer services (adequate or inadequate), and road access (yes or no).

### 2.3 STATISTICAL ANALYSIS

The analysis first describes the population at risk. A more in depth analysis compares individuals who experience some support and activity limitations with individuals who do not experience activity limitations. Health status differences are analyzed within and between the two

groups, controlling for social-demographic characteristics. Ecological variables and perception of health services are also compared.

Data analysis was descriptive (percentages) and involved chi-square tests of significance. Significance was reported at 0.05 and 0.001 levels of probability. Caution must be exercised in the interpretation of significance. For instance, small differences in large samples can be very important but not significant or small differences may be significant, but not informative (Grosf and Sardy 1985).

### 3 POPULATION AT RISK

The survey describes a population of approximately 199,782 First Nation and Labrador Inuit adults (15 and over) who may be at risk for developing a need for support or an activity limitation. Poor social-economic environment is associated with the increased risk of developing limitations. In First Nation and Inuit communities, previous surveys confirm that social-economic conditions are poor (APS 1991). Education attainment reflects the potential of poverty persisting. Of First Nations and Labrador Inuit people, nearly 80% had not attained a high school education.

Most First Nation and Labrador Inuit adults (66%) live in small communities (<1000 people). Although 78% live in communities that have year around road access, 33% live in communities isolated from health services. A large number of people (67%) live in non-isolated communities located in rural areas that are some distance from large urban centers. Overall, 74% of people reside in communities where there is no special purpose housing facilities designed to provide for physical, social and emotional conditions, or disability. Approximately 55% live in communities where 50% of the houses are inadequate. A large number of people (70%) live in communities where overcrowding is persistent in that on average four or more people live in a household. However, 80% of people live in communities that have adequate water and sewer systems.

#### 3.1 SOCIAL DEMOGRAPHICS

Forty-nine percent of the population is women and 51% are men. Forty-two percent of adults were 15 and 29 years, 44% were 30 and 54 years, and 14% were 55 years or older. A little over half (54%) stated that they have a partner opposed to 46% who are single, divorced or widowed. There was little difference between men and women. Forty-three percent indicated that they have a partner and children under eighteen living at home, 12% have a partner and no children at home, 20% are single and have children under eighteen living at home, and 25% are single and have no children living at home.

More women (65%) reported that they were single parents with children living at home, whereas more men (66%) indicated that they are single without children (Figure 4). Of those that have a partner, slightly more women (53%) stated that they have children at home, whereas more men (56%) have no children living at home. Most women, aged 15-29 years, were either single (33%) or in a partnership with children living at home (44%) (Figure 5). Most men in this age group were single with no children (43%) or had a partner and children at home (30%). Most women aged 30-54 years were either single with children at home (25%) or had a partner and children at home (57%). Most men in this age group were single without children (22%) or had a partner and children at home (54%). Most women, aged 55 years and older, were more often single with no children at home (40%) or with a partner and no children at home (33%). Older men were living more often with partners (40%) than single (32%).



FIGURE 4 – GENDER AND LIVING ARRANGEMENTS %

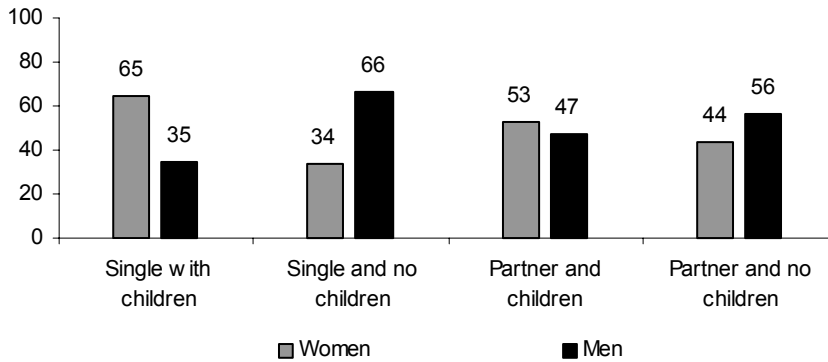
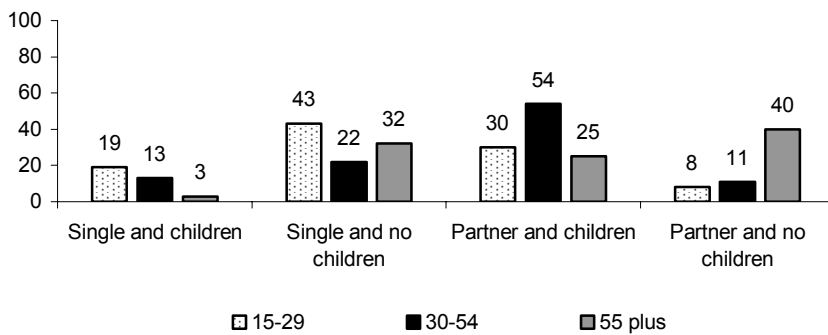
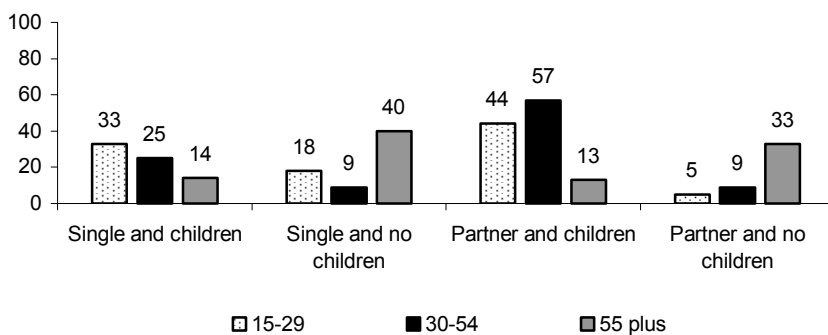


FIGURE 5 – LIVING ARRANGEMENTS BY AGE AND GENDER %

Men



Women



### 3.2 HEALTH STATUS

Nearly half of all First Nations and Labrador Inuit people (48%) reported that they have poor to fair health, and 46% reported that they had been told by a health care professional that they have at least one health problem. Health status decreased with age. The majority of people aged

15-29 years reported very good to excellent health (62%). Only half of the people aged 30-54 years reported very good to excellent health and 73% of people aged 55 years and older reported poor to fair health. The same was true for health problems. More younger people reported no health problems (72%), while the majority of the oldest group reported having at least one health problem (84%). In general, men (55%) reported very good to excellent health and no health problems (60%), while half of all women reported having at least one health problem (52%) and poor to fair health (52%). Younger men reported better health than did younger women (Table 5). There were little differences between men and women in terms of self-perceived health status in the middle aged group. However, slightly more women reported having at least one health problem. In the 55 years and older group, a larger number of both women and men had reported poor health status, but again more women ranked their health as poor and reported a greater burden of disease than did men.

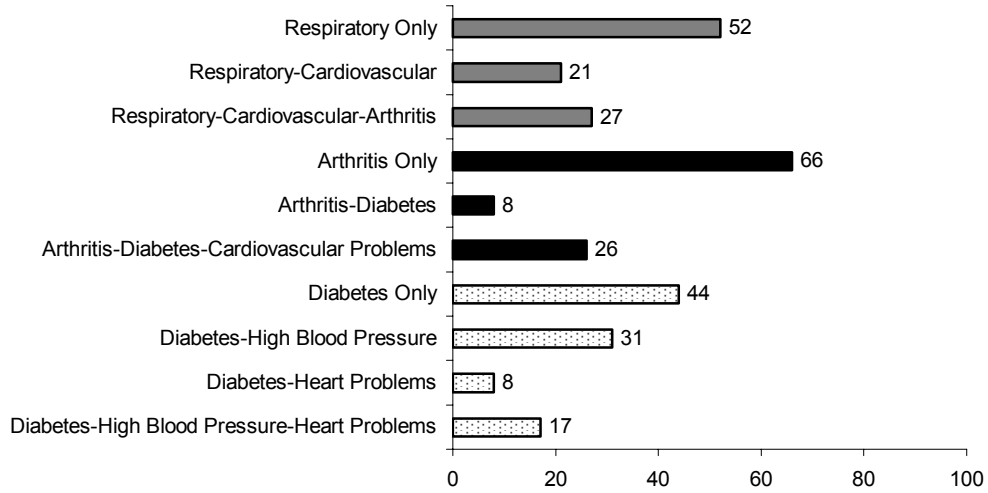
TABLE 5 – HEALTH STATUS BY AGE AND GENDER %

Health Status	15 – 29 Years		30 – 54 Years		55 and over	
	Male	Female	Male	Female	Male	Female
Very Good-Excellent	67	57	51	49	31	24
Poor-Fair	33	43	49	51	69	76
No Chronic Conditions	77	66	56	44	20	13
At least One Chronic Condition	24	34	44	56	80	87

The prevalence of specific chronic conditions are: diabetes (11%); respiratory problems (i.e., breathing problems or asthma) (14%); muscular skeletal condition (arthritis) (16%); and cardiovascular problems (high blood pressure or heart problems) (23%). A number of people who reported diabetes, arthritis, or respiratory problems also reported having another chronic condition.

Of people reporting diabetes (Figure 6), 44% indicated that they had diabetes only, 31% also have high blood pressure, 8% also have heart problems, and 17% also have high blood pressure and heart problems. Of people reporting arthritis, 66% have arthritis only, 8% also have diabetes, and 26% also have diabetes and a cardiovascular problem. Of people reporting a respiratory problem, 52% have a respiratory problem only, 21% also have a cardiovascular problem, and over a quarter (27%) also have arthritis and a cardiovascular problem.

FIGURE 6 – DIABETES, ARTHRITIS, AND RESPIRATORY CO-MORBIDITY



In Table 6, although fewer young people reported a chronic disease problem, the level of morbidity is relatively high and illustrates the potential of co-morbidity and activity limitations in the future. Morbidity and co-morbidity increased significantly with age.

TABLE 6 – CHRONIC CONDITIONS BY AGE %<sup>1</sup>

<b>Chronic Conditions</b>	<b>15 – 29 Years</b>	<b>30 – 54 Years</b>	<b>55 and over</b>
Arthritis	5	18	48
Respiratory	12	14	30
Cardiovascular	11	24	59
Diabetes	4	12	30
<b>Diabetes Only and Co-Morbidity</b>	<b>15-29 Years</b>	<b>30 – 54 Years</b>	<b>55 and over</b>
Diabetes Only	3	6	8
Diabetes & High Blood Pressure	1	4	10
Diabetes & Heart Problems	-	1	3
Diabetes, High Blood Pressure, & Heart Problems	-	1	9
<b>Arthritis Only and Co-Morbidity</b>	<b>15-29 Years</b>	<b>30 – 54 Years</b>	<b>55 and over</b>
Arthritis Only	5	11	19
Arthritis & Diabetes	-	3	9
Arthritis, Diabetes, Cardiovascular Problems	-	4	20
<b>Respiratory Only and Co-Morbidity</b>	<b>15-29 Years</b>	<b>30 – 54 Years</b>	<b>55 and over</b>
Respiratory Only	8	7	8
Respiratory & Cardiovascular Problems	4	4	8
Respiratory Cardiovascular Problems & Arthritis	-	3	14

There were some differences between men and women. Younger women reported higher rates of respiratory, cardiovascular, and arthritis problems, whereas younger men reported higher rates of diabetes. Morbidity increased for both men and women in the middle-aged and older age group, with a general trend towards higher levels of morbidity and co-morbidity among women.

<sup>1</sup> Cells with no information reflect no condition of that type or population numbers < 250.

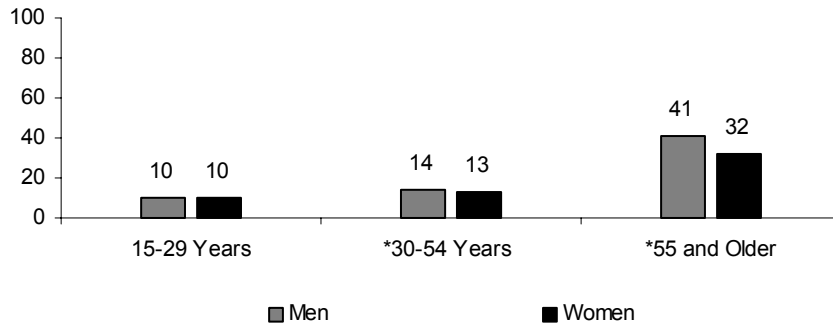
TABLE 7 – CHRONIC CONDITIONS BY AGE AND GENDER %<sup>2</sup>

Chronic Conditions	15 – 29 Years		30 – 54 Years		55 and over	
	Male	Female	Male	Female	Male	Female
Arthritis	3	7	14	21	43	54
Respiratory	9	14	12	17	27	32
Cardiovascular	8	13	24	23	57	60
Diabetes	5	2	10	14	24	35
Diabetes Co-Morbidity	*15 – 29 Years		30 – 54 Years		55 and over	
	Male	Female	Male	Female	Male	Female
Diabetes only	3	1	4	8	7	10
Diabetes & High Blood Pressure	2	1	4	4	6	13
Diabetes & Heart Problems	-	-	1	1	3	3
Diabetes, High Blood Pressure, & Heart Problems	-	-	1	1	8	9
Arthritis Co-Morbidity	15 – 29 Years		30 – 54 Years		55 and over	
	Male	Female	Male	Female	Male	Female
Arthritis only	3	7	8	16	19	19
Arthritis & Diabetes	-	-	2	2	6	10
Arthritis, Diabetes, & Cardiovascular Problems	-	-	4	3	18	25
Respiratory Co-Morbidity	*15 – 29 Years		30 – 54 Years		55 and over	
	Male	Female	Male	Female	Male	Female
Respiratory only	6	11	6	10	7	8
Respiratory & Cardiovascular Problems	3	3	3	4	7	9
Respiratory, Cardiovascular Problems & Arthritis	-	-	3	3	13	15

Hearing impairments were also high. Fifteen percent of all First Nations and Labrador Inuit people have difficulty hearing a conversation. Hearing problems increased for men as they got older (Figure 7). Approximately 20% of people with hearing problems reported poor health status.

<sup>2</sup> Cells with no information reflect no condition of that type or population numbers < 250.

FIGURE 7 – HEARING PROBLEMS AND GENDER DIFFERENCES, CONTROLLING FOR AGE %



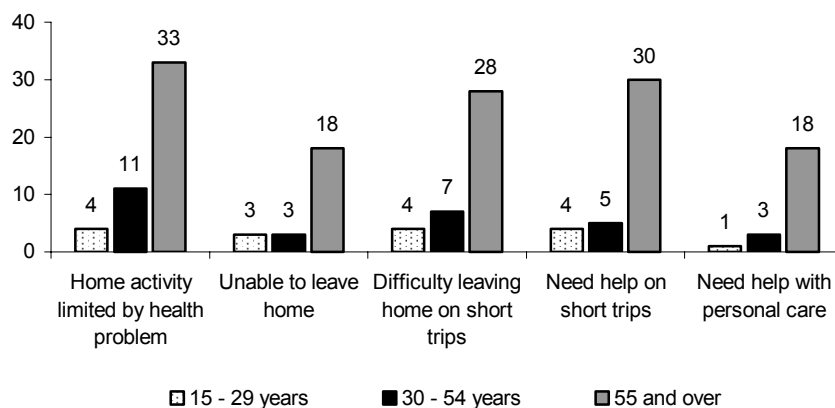
\* Significant at P=0.001

## 4 LIMITATIONS, HEALTH STATUS, AND ENVIRONMENT

### 4.1 SOCIAL DEMOGRAPHICS AND LIMITATIONS

Most First Nation and Inuit people (85%) reported that they did not require help with personal care or require an attendant for short trips. In addition, they were not house bound and did not have difficulties going on short trips. Nevertheless, 15% experienced at least one limitation (activity or support). This experience increased for older people (Figure 8).

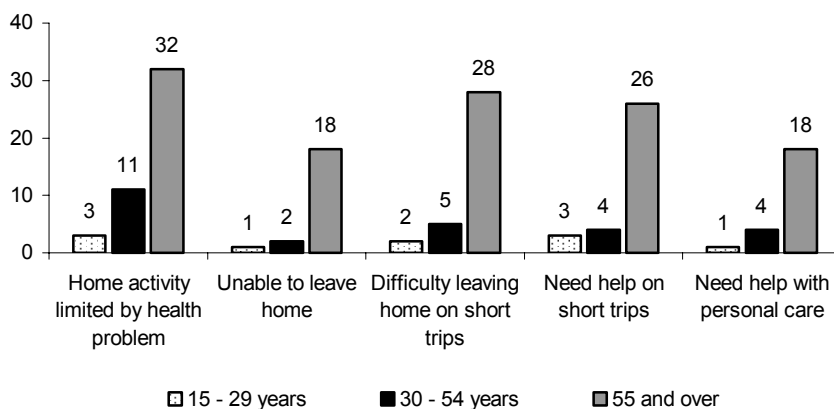
FIGURE 8 – PROPORTION OF PEOPLE REPORTING LIMITATIONS BY AGE %



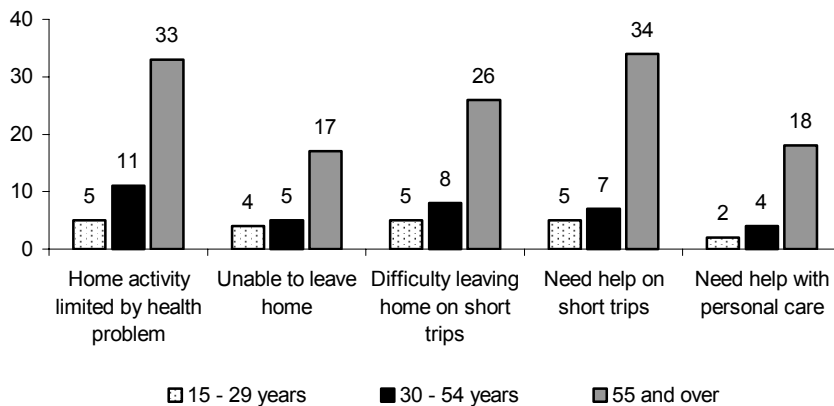
Few gender differences were apparent (Figure 9). Older men and women reported similar activity limitations, whereas slightly more women than men reported limitations in the younger and middle- aged groups.

FIGURE 9 – LIMITATIONS BY AGE AND GENDER %

Men



Women

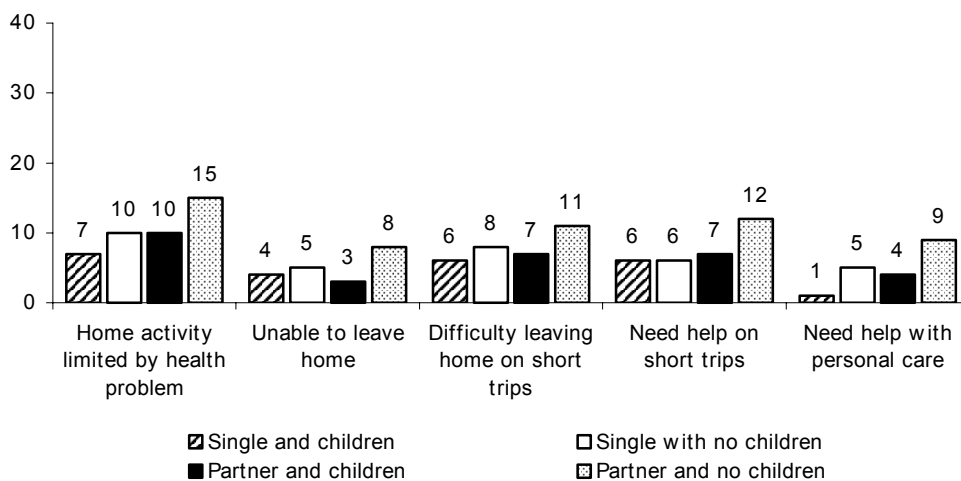


Activity limitations experienced by men and women in different living arrangements revealed some interesting differences (Figure 10). Single women with no children reported the most limitations, followed by women with a partner and no children living at home. Only Men with a partner and no children at home reported a similar level of limitations.

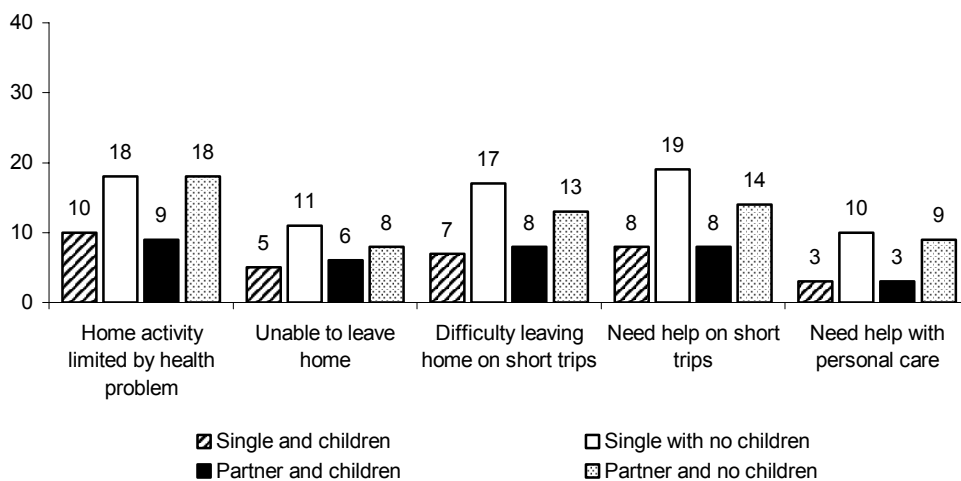


FIGURE 10 - LIMITATIONS BY LIVING ARRANGEMENTS AND GENDER %

Men



Women



Statistically Significant at P < 0.05

## 4.2 LIMITATIONS AND HEALTH STATUS

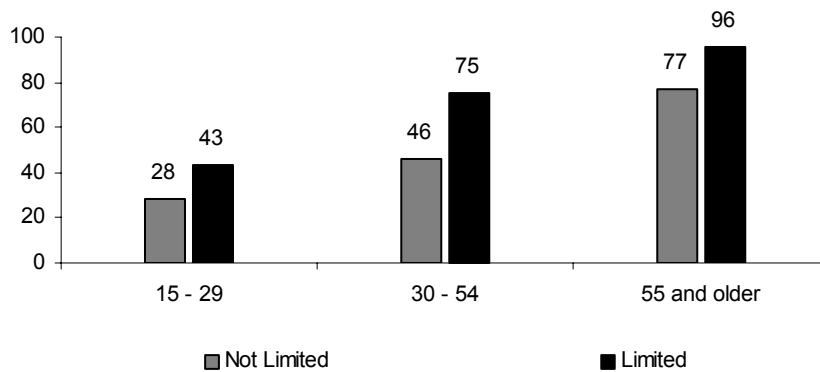
### 4.2.1 GENERAL HEALTH

Of people who experienced no limitations, 41% reported that they had a health problem diagnosed by a health professional, and a similar proportion (45%) reported poor to fair health.

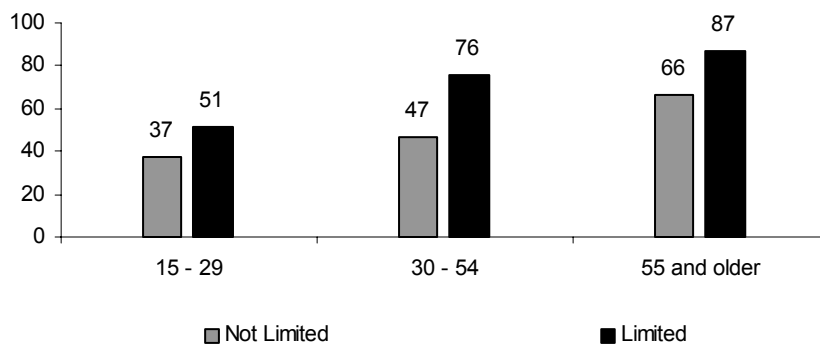
People with an activity limitation reported much poorer health. Nearly three-quarters (74%) had a health problem, and a similar proportion (75%) reported poor to fair health. The vast majority (84%) who had a health problem also reported poor to fair health. Women reporting limitations had poorer health status than women reporting no limitations. The same was true for men. Women also reported slightly poorer health status than did men who reported activity limitations. Health status also decreased with age in both groups, which perhaps indicates not only the impact of disease, but the experience of poverty over a lifetime (Figure 11).

FIGURE 11 – POOR HEALTH STATUS BY AGE, COMPARING PEOPLE WITH ACTIVITY LIMITATIONS AND PEOPLE WITHOUT LIMITATIONS %

At Least One Chronic Condition



Poor to Fair Health

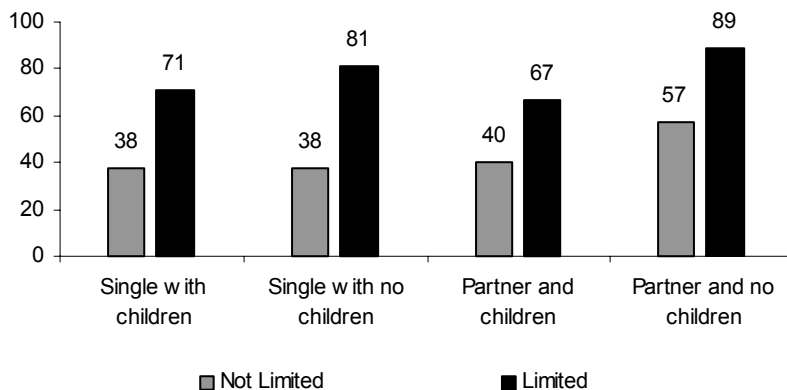


All cross tabulations are statistically significant at P=0.001

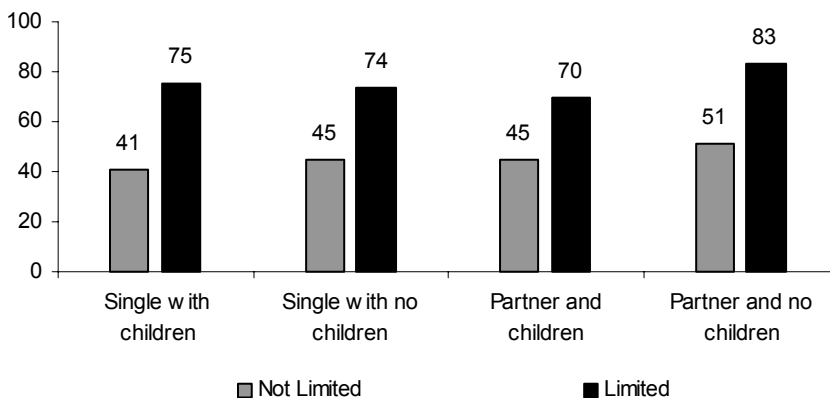
“Having a partner and/or children at home” suggests that some form of support is available within the household and that support may improve health status. However, people with limitations, regardless of living arrangements, continued to report poor health status (Figure 12).

FIGURE 12 – POOR HEALTH STATUS BY LIVING ARRANGEMENTS, COMPARING PEOPLE WITH ACTIVITY LIMITATIONS AND PEOPLE WITHOUT LIMITATIONS %

At Least One Chronic Condition



Poor to Fair Health



Statistically significant at P=0.001

4.2.2 CHRONIC CONDITIONS

Although the First Nation and Inuit Regional Health Survey did not directly link impairment with functional limitations, a profile of people who report activity limitations and specific chronic conditions can be reported (Figure 13). People reporting activity limitations reported a much higher burden of cardiovascular disease (47%), arthritis (45%), respiratory problems (31%), and diabetes (27%). Women with activity limitations reported slightly higher prevalence of arthritis, respiratory illness, and diabetes than did men with limitations (Figure 14).

FIGURE 13 – CHRONIC CONDITION PREVALENCE, COMPARING PEOPLE WITH ACTIVITY LIMITATIONS AND PEOPLE WITHOUT LIMITATIONS %

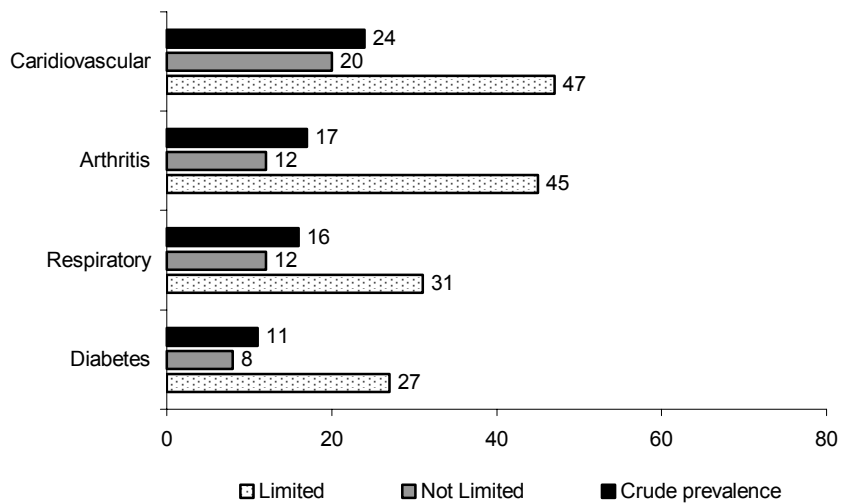
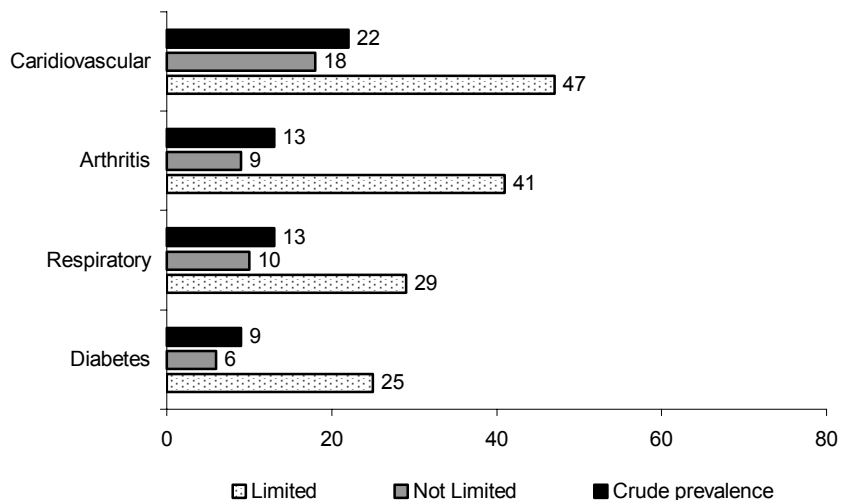
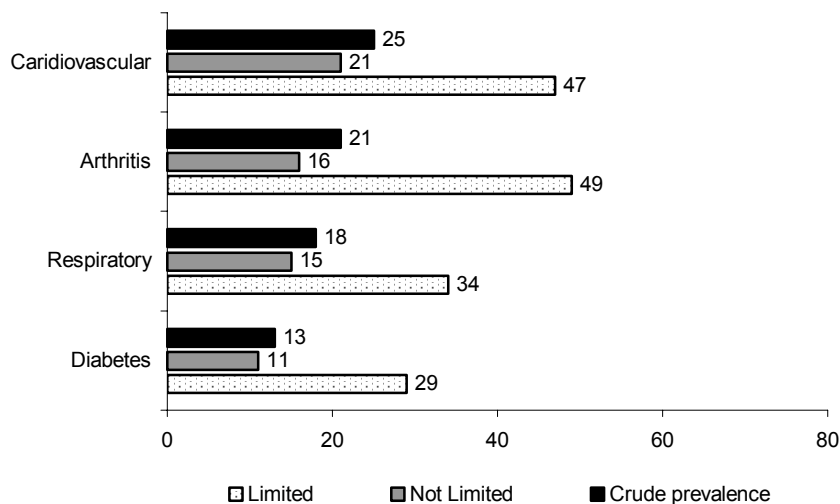


FIGURE 14 – CHRONIC CONDITION PREVALENCE AND GENDER, COMPARING PEOPLE WITH ACTIVITY LIMITATIONS AND PEOPLE WITHOUT LIMITATIONS %

Men



Women



Statistically significant at P=0.001

Age differences were apparent (Table 8). People, aged 15-29 years, who reported activity limitations reported a higher proportion of cardiovascular, arthritis, respiratory and diabetes conditions than did people without limitations. People aged 55 and older who reported activity limitations had a higher burden of disease than did people without limitations.

TABLE 8 – CHRONIC CONDITIONS AND AGE, COMPARING PEOPLE WITH ACTIVITY LIMITATIONS AND PEOPLE WITHOUT LIMITATIONS

Chronic Condition	15-29 Years		30-54 Years		55 and Over	
	Not Limited	Limited	Not Limited	Limited	Not Limited	Limited
Cardiovascular	10	15	21	39	50	74
Arthritis	4	18	14	39	38	68
Respiratory	11	19	12	30	23	42
Diabetes	3	11	11	21	22	44

Statistically Significant at P=0.001

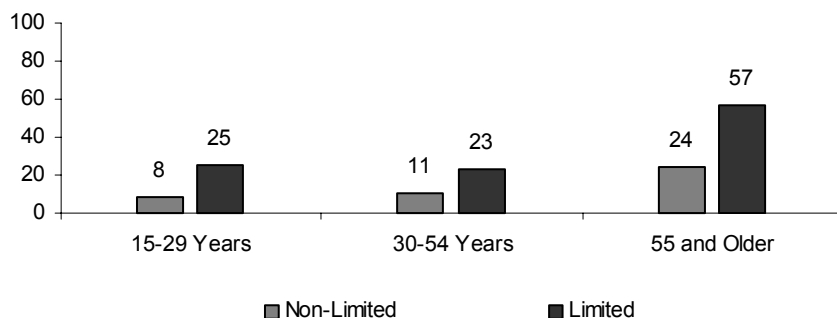
People with more complex co-morbidity reported more activity limitations, and this was especially true for men (Table 9). In general, men who reported complex co-morbidity were unable to leave home or had difficulty leaving home to go on short trips. They also needed help with personal care. Women who reported complex co-morbidity were more likely to need help on short trips.

TABLE 9 – PEOPLE WITH ACTIVITY LIMITATIONS BY COMPLEX CO-MORBIDITY AND GENDER %

Complex Co-morbidity	Home activity limited by a health problem		Unable to leave home		Difficulty leaving home on short trips		Need help on short trips		Need help with personal care	
	M	F	M	F	M	F	M	F	M	F
Diabetes & Cardiovascular	44	42	21	17	31	28	29	32	19	20
Arthritis, Diabetes & Cardiovascular	58	60	32	21	44	39	44	43	34	29
Respiratory, Cardiovascular & Arthritis	52	50	24	17	34	37	37	43	32	27

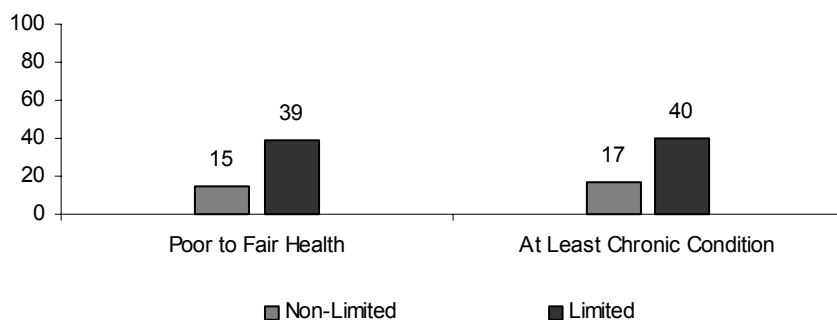
People who reported activity limitations (36%) also had more hearing problems, and men (38%) did so more than women (35%). Age differences were apparent (Figure 15). People, aged 55 years and older, who reported activity limitations had more hearing problems (57%). However, a large number of people under 55 had hearing problems as well. People who reported activity limitations and hearing problems (Figure 16) also reported poor health status (40%).

FIGURE 15 – HEARING PROBLEMS AND AGE, COMPARING PEOPLE WITH ACTIVITY LIMITATIONS AND PEOPLE WITHOUT LIMITATIONS %



Statistically significant at P=0.001

FIGURE 16 – HEARING PROBLEMS AND POOR HEALTH STATUS, COMPARING PEOPLE WITH ACTIVITY LIMITATIONS AND PEOPLE WITHOUT LIMITATIONS %



Statistically significant at P=0.001

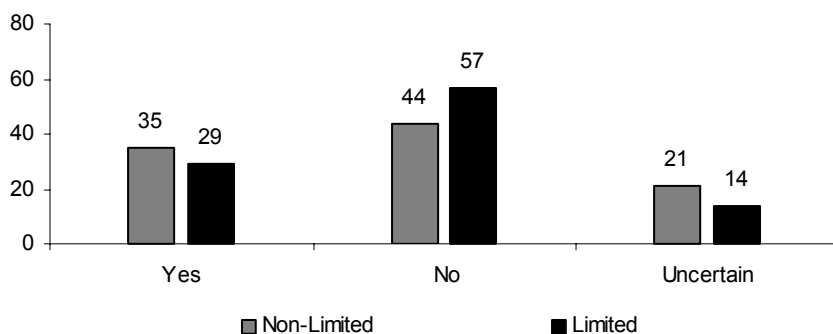
### 4.3 LIMITATIONS AND PERCEPTIONS OF HEALTH SERVICE DELIVERY

Over a third of people with activity limitations reside in communities that have already signed health transfer agreements (34%) or live in communities that are in health transfer negotiations (39%). Twenty-seven percent reside in communities that have not entered in to health transfer negotiations.

Geographic proximity to health care services for people with limitations will be a major health care challenge facing First Nations and the Labrador Inuit. Thirty percent of people who experience limitations live in isolated communities, and 13% reside in communities that have no year round road access. Non-isolated communities may also experience problems providing accessible medical transportation for a growing number of people who have complex co-morbidity and activity limitations.

A vast majority of First Nation and Labrador Inuit people had stated that they do not have the same level of health services as the rest of Canadians. There are some differences in perception between people with activity limitations and people with no limitations on the availability of health services (Figure 17). Only 29% of people with activity limitations, compared to 35% of people with no limitations, agreed that they have the same level of health services.

FIGURE 17 – PERCEPTION OF SAME LEVEL OF HEALTH SERVICES, COMPARING PEOPLE WITH ACTIVITY LIMITATIONS AND PEOPLE WITHOUT LIMITATIONS %

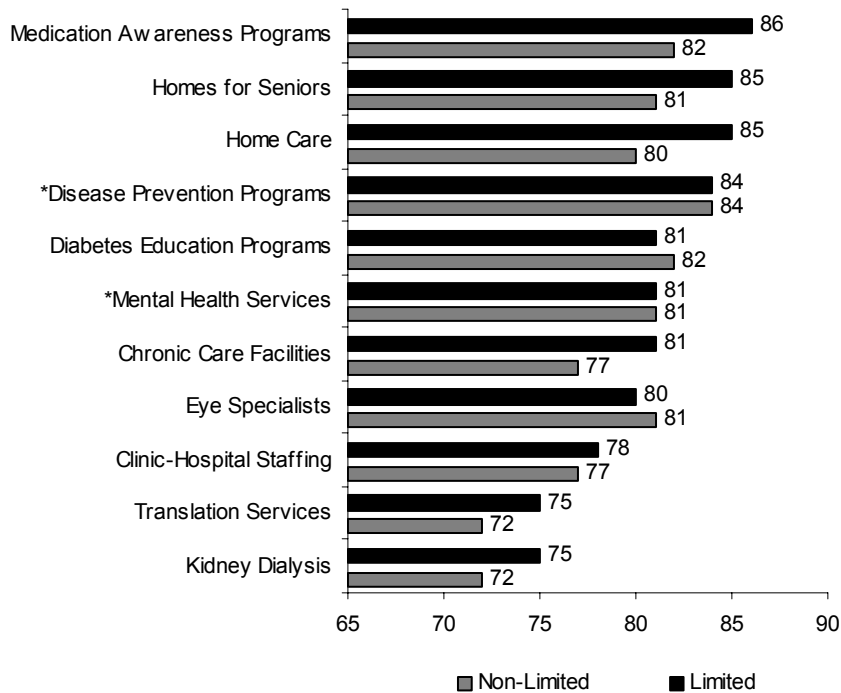


Significant at P=0.001

There are many health service areas in need of improving according to First Nation and Labrador Inuit people (Figure 18). Again, there were significant differences between people with activity limitations and people with no limitations. The differences were greatest for continuing care services. The group reporting limitations identified senior homes, home care services, medication awareness programs, chronic care facilities, kidney dialysis services and translation services as the areas in need of greatest improvement.



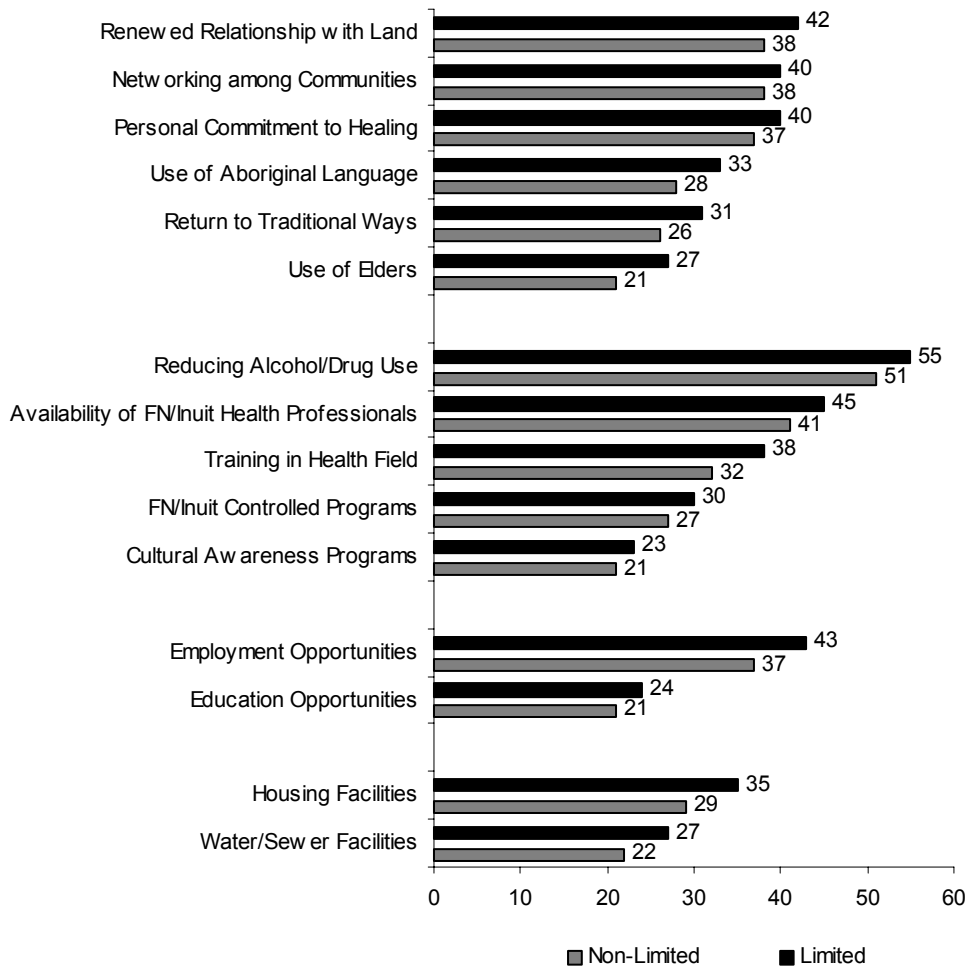
FIGURE 18 – HEALTH SERVICE AREAS IN NEED OF IMPROVEMENT, COMPARING PEOPLE WITH ACTIVITY LIMITATIONS AND PEOPLE WITHOUT LIMITATIONS %



Significant at P < 0.05  
 \*No significant difference.

More people with limitations (81%) favored a return to traditional ways in order to promote community wellness than did people without activity limitations (79%). There were also differences in the perception of progress made in factors important for community wellness (Figure 19). People with activity limitations were generally less optimistic, regardless of area: infrastructure development (housing, water, sewer), socio-economic opportunities (education and employment), traditionality (language use, land use, healing, networking, and traditional ways), and self-government developments (FN/Inuit health professionals, training in health field, cultural awareness programs, reduction in alcohol/drug use).

FIGURE 19 – LACK OF PROGRESS IN AREAS IMPORTANT FOR COMMUNITY WELLNESS, COMPARING PEOPLE WITH ACTIVITY LIMITATIONS AND PEOPLE WITHOUT LIMITATIONS %



Statistically Significant at P=0.001

## 5 DISCUSSION AND RECOMMENDATIONS

### 5.1 DISCUSSION

The First Nations and Labrador Inuit Regional Health Survey clearly suggests that First Nations and Labrador Inuit people are at high risk of developing activity limitations and a need for support. Morbidity rates for cardiovascular conditions, arthritis, respiratory conditions, and diabetes are high. A substantial number of people who report diabetes, arthritis, or respiratory problems have also reported that they have another chronic condition. Complex co-morbidity such as arthritis, diabetes, and cardiovascular problems are particularly high. People 55 years and older have the most complex co-morbidities, but a good proportion of people who are middle-aged also report co-morbidities. Younger people are also reporting co-morbidities, particularly diabetes and high blood pressure and respiratory and cardiovascular problems.

People with activity limitations represent a particular group in First Nation and Labrador Inuit communities. The data suggests that people who are middle-aged or older experience activity limitations, but a large proportion of young people also reported limitations. Few gender differences were apparent. Older men and women reported similar activity limitation, whereas slightly more women than men reported limitations in the younger and middle-aged groups. Although the family is the first line of support in a continuing care system, the living arrangements of First Nations and Labrador Inuit people suggest that people, regardless of age, may not have the necessary support in the household. For instance, single women who have no children living at home reported the most activity limitations, followed by women with a partner and no children living at home. Only men with a partner and no children at home reported a similar level of limitations.

People with activity limitations reported much poorer health status than did people who had no limitations. There were unique gender, age, and living arrangement differences. Women reporting limitations had poorer health status than women reporting no limitations. The same was true for men. Women also reported slightly poorer health status than did men who reported limitations. Health status decreased with age in both groups. However, poor health status was high in the young population.

Although the survey did not directly link impairment with functional limitations, a distinct profile of people with and without activity limitations emerged. People with limitations reported higher morbidity, regardless of gender. Age differences were apparent. Younger people reporting activity limitations had a higher burden of disease than did younger people without limitations. The burden of disease was higher for the older age group reporting activity limitations. People with complex co-morbidity reported more activity limitations. Gender differences were apparent. Men with complex co-morbidity reported more activity limitations, with the exception of women who reported a greater need for help on short trips.

People who report activity limitations also had more hearing problems, and men did so more than women. Age differences were apparent. People, aged 55 years and older, who reported activity limitations had more hearing problems. However, a large number of people under 55 had hearing problems as well.

Disability and disabling co-morbidity will place a disproportionately large burden on the health care system. For instance, the burden of diabetes and its complications is large and will increase, as the population grows older. Effective primary, secondary, and tertiary prevention strategies are needed on top of the programs already in place. Programs are needed that prevent blindness, lower-extremity amputations, cardiovascular disease, and adverse outcomes of pregnancy among persons with diabetes. Young people who develop this condition early will experience

activity limitations, which may affect both the education system and the health care system. Older adults are reporting very high rates of diabetes co-morbidities and the functional limitations associated with complex co-morbidities. The same applies for people experiencing respiratory co-morbidity and arthritis co-morbidity.

Early development of complex co-morbidity, high rates of morbidity in middle-aged and older people, gender differences, and a relatively high prevalence of chronic conditions in younger people are a cause for concern.

Isolation and non-isolation from health services will complicate the development of this system. People with activity limitations living in isolated regions may have to travel great distances to access continuing care services.

Barriers to continuing care services are also due to jurisdictional problems between federal departments, between provincial governments and the federal government, and between provincial governments and First Nation and Labrador Inuit governments.

At this time, satisfaction with existing services is quite low, and improvements are required. People with activity limitations were more likely to recognize that they did not have the same level of health services as other Canadians. They were also more inclined to see a greater need for improving access to senior residential homes, medication awareness programs, chronic care facilities, kidney dialysis services, and translation services. They were also less optimistic than other people in terms of the progress made in factors important for community wellness.

These findings have important implications for the development of a continuing care system for First Nations people on-reserve and the Labrador Inuit. The data points to an escalating burden of chronic illness related disabilities and activity limitations. Since current programs are inadequate to current needs, planning for future needs is urgently required. The down-stream costs of not providing adequate home care and continuing care services will be huge. Needless to say, the deterioration in the quality of life of people with disabilities and activity limitations will also be enormous.

## **5.2 RECOMMENDATIONS**

### **5.2.1 MEASUREMENT ISSUES**

- Future surveys should adopt more comprehensive and internationally recognized measures of disability, handicap, and impairment and rethink these measures to reflect the cultural-social-geographic-health and-economic context of First Nations and the Labrador Inuit.
- Include functional and activity limitations questions using item formats comparable to those used in the Aboriginal Peoples, HALS, and National Population Health Surveys to facilitate comparative analysis with other populations.

### **5.2.2 HEALTH SERVICE NEEDS**

- Continuing care services need to be effective and integrated, and provide health care that is in accordance with the Canada Health Act.

- Resolution of jurisdictional problems related to continuing care services must be resolved with active First Nations and Labrador Inuit participation.
- Development of on-reserve home care services is urgently required to meet the expanding burden of chronic illness and disability-related activity limitations.
- Failure to develop these services will result in rapidly escalating health care costs at the tertiary level as First Nations and Labrador Inuit people with disabilities and chronic conditions are either hospitalized or related to urban centers.
- Provincial and regional health authorities must recognize the downstream costs associated with poor home care and continuing care services and must advocate on behalf of First Nations and Labrador Inuit communities for improvements in these services.
- First Nations and Labrador Inuit leadership must continue to press for changes in funding formulas for non-insured health benefits and community services, particularly in transferred communities. Without substantial increases in funding, First Nations and Labrador Inuit people with chronic illnesses and disabilities will suffer increasing limitations in their daily activities.

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