

**FIRST NATIONS PEOPLE WITH DISABILITIES:
AN ANALYSIS OF
SERVICE DELIVERY IN MANITOBA**

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**A Thesis
Submitted to the Faculty of Graduate Studies
in Partial Fulfilment of the Requirements for the Degree of**

MASTER OF SCIENCE

**Department of Community Health Sciences
University of Manitoba
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BY

MONIKA WENDY FRICKE

**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University
of Manitoba in partial fulfillment of the requirements of the degree
of
MASTER OF SCIENCE**

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ABSTRACT

Equal access and participation issues are at the forefront of the current disability advocacy movement. People with disabilities in the international community are demanding a change in attitude and policies which affect their inherent right as citizens to full participation in society. The inequalities in access to services experienced by Aboriginal persons with disabilities in Canada are magnified by the unique socioeconomic, political, environmental and cultural barriers. The existing infrastructure has often resulted in an ineffective, unaccountable and occasionally inappropriate web of service delivery for Aboriginal persons with special needs.

This document reviews the current structure of service delivery to First Nations people with disabilities, particularly those living in remote areas of Manitoba. A description and critical examination of rehabilitation services, home care services, housing issues, community access, and mobility devices emphasizes the disparities in access to services faced by First Nations people with disabilities. Qualitative data obtained through ethnographic case studies provides a First Nation consumer perspective of current services. Key informant interviews with health care planners and providers offer inside perspectives of the system itself. Summary recommendations are provided.

It is crucial that health care providers grasp the complexities surrounding Aboriginal health care if services are to be delivered in a cross-culturally sensitive fashion. Recognition of these issues is equally important for those involved in current negotiations surrounding Aboriginal self-government and health transfer agreements. A more coordinated and sensitive model of service delivery to Manitoba's First Nations people with disabilities is essential if the equalization of opportunities is to be realized.

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A Note About Terminology

The term *Aboriginal* in its Canadian context, includes all indigenous peoples: *Inuit* (formerly referred to as Eskimo), *Métis* (of mixed origin) and *First Nations* (formerly referred to as Indian) (Royal Commission on Aboriginal Peoples, 1996, p. viii).

"Registered" or "status" Aboriginal persons encompass the overall group of Aboriginal peoples recognized under the *Indian Act*, regardless of any existing treaty. "Treaty" Aboriginal persons refers to those specific groups who have existing treaties with the federal government. "Reserves" refers to "rural and remote tracts of land granted as part of treaty negotiations" (O'Neil, 1995, p.560).

CHAPTER ONE: INTRODUCTION

Equal access and participation issues are at the forefront of the current disability aids advocacy movement. People with disabilities in the international community are demanding a change in attitude and policies which affect their inherent right as citizens to full participation in society.

Referred to as the "last civil rights movement" (Driedger, 1989), disability issues are being brought to the attention of both the politicians and the public by advocacy groups. "Disability" has been defined by the World Health Organization as the functional limitations of an individual, resulting from a physical and/or biological impairment (WHO, 1980, p. 28). Persons with disabilities contend that many of the handicaps they face are a direct result of the structural and attitudinal barriers created by society's lack of awareness (Crewe, 1979; French, 1994b; Legge, 1993; Zola, 1982). The equalization of opportunities for persons with disabilities has become the primary focus of the independent living movement. "Independent living" has been defined by Denson (1988) as

a concept, a policy, a set of community based services and programs, and a civil rights movement. (It is) the freedom to participate in the community fully and to have access to housing, transportation, health care, employment, and education... Independent living is reflective of a self-determined and self-directed lifestyle which permits the individual to make meaningful choices and solutions. (as cited in Schlaff, 1993, p.946)

Particularly in North America, political agendas of advocacy groups for independent living have focused on the equal rights of the individual. However, in more traditional cultures, this emphasis on individual rights may be overshadowed by the needs of the community as a whole. In many Canadian

Aboriginal communities for instance, where housing, sanitation, and education standards are considered less than satisfactory, community development issues may take precedence over all else. Nonetheless, as the rates of disability indicate, increased focus on meeting the needs of Aboriginal persons with disabilities is warranted.

The optimization of a return to independent functioning has been the hallmark of medical rehabilitation. Based on the traditional medical model of health and disability, rehabilitation efforts have concentrated primarily on minimizing impairments and functional limitations of the individual. This focus on the individual is in direct contrast with the independent living movement, which emphasizes the role of society in the creation of barriers to independence.

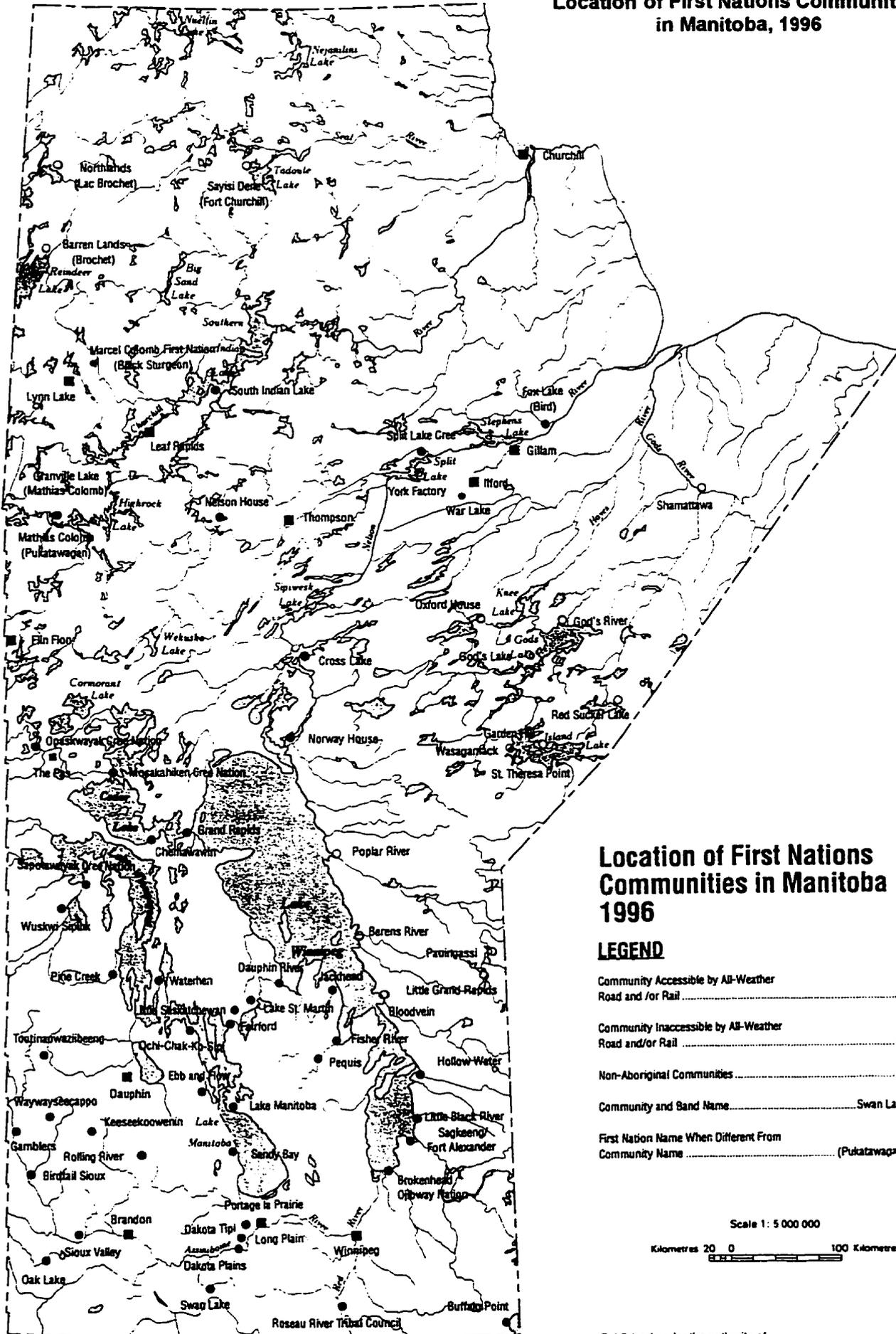
Contemporary consumer literature suggests that rehabilitation services do not adequately prepare the individual with a disability for the long-term challenges of independent living (DeJong, 1993; Johnson, 1993; Thomas & Parry, 1996; Zola, 1979). Recipients of rehabilitation are often faced with gaps in professional awareness and understanding of the unique needs, expectations, and social context of their experience (DeJong, 1979; Haley et al, 1994; Werner, 1992; Williams, 1987). The World Institute on Disability has stated that independence "is not measured by the quantity of tasks one can perform without assistance, but rather the quality of life one can have with help" (as cited in Boschen & Krane, 1992, p. 84). An individual's capacity for independent living is influenced by the availability of appropriate technological supports, health care services, supportive family and friends. The accessibility of housing, transportation and the community play a vital role in the opportunity to participate in a given environment. Persons with disabilities face isolation and disenfranchisement where housing is not readily modified to accommodate

wheelchair access and the outdoor environment is too rugged to permit easy manoeuvrability with a mobility aid. Adverse attitudes of the community, a person's network of family and friends, as well as health care providers can create and perpetuate a variety of barriers to participation.

The independent living paradigm refers specifically to persons with disabilities, but it can simultaneously provide a vision of the overall concept of self-determination for Canada's indigenous peoples. Independent living represents the emancipation of a traditionally disenfranchised group. The inequalities faced by Aboriginal people with disabilities in Canada are magnified by unique socioeconomic, political, environmental, and cultural barriers. Independent living is challenged even further by geographical isolation. Of the sixty-one First Nation communities in Manitoba, eighteen are accessible only by air for ten months of the year (see Figure 1). The current structure of service delivery to First Nations people with special needs has often resulted in a web of ineffective, unaccountable, and often inappropriate services. Many health care providers and consumers are left unclear about where to turn for support services or funding resources for those with special needs as a result of the jurisdictional debate over responsibility for Aboriginal health care. Confusion arises about whether the accountability rests with the federal government's obligation to Aboriginal peoples, with the provincial government's mandate for health care or with the health programs directed by the local band council. The lack of access to provincial programs and services in remote Aboriginal communities has often forced individuals and families to move to larger urban settings. Independent living for some people may only come at the price of separation from one's home community.



Figure 1
Location of First Nations Communities in Manitoba, 1996



1.1 OBJECTIVES

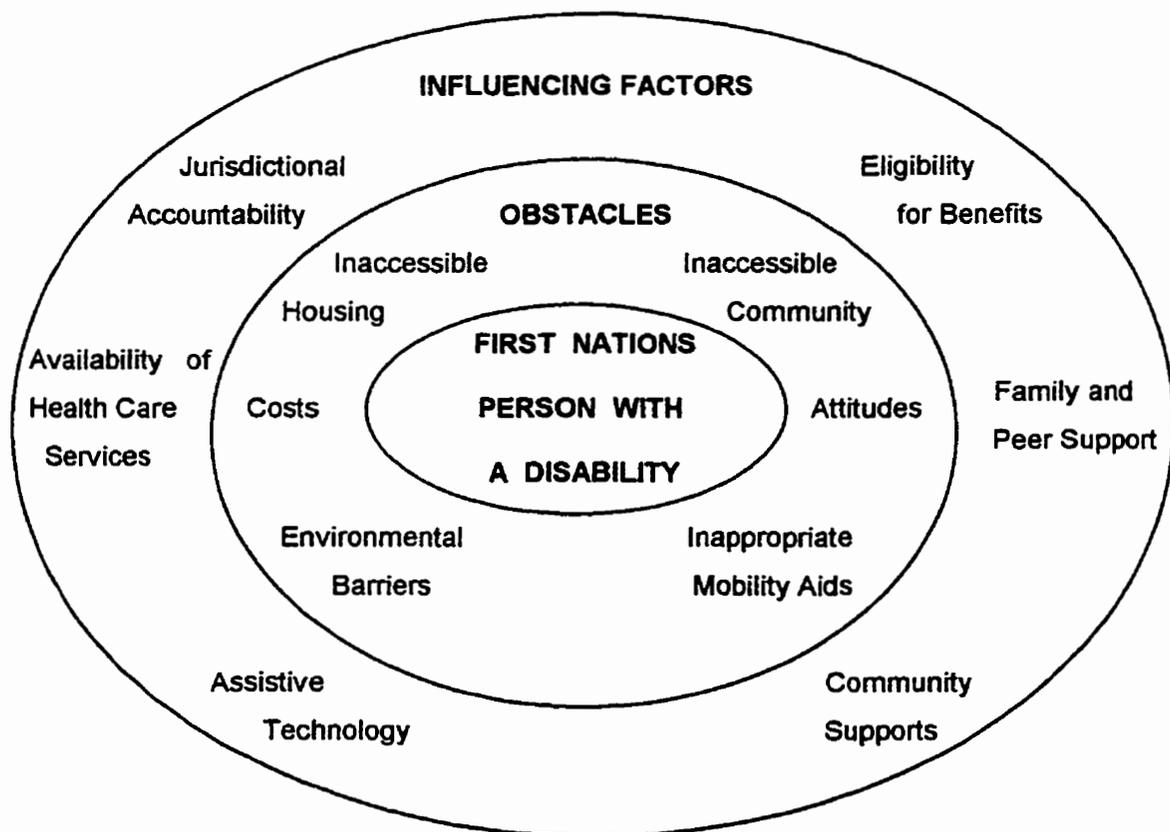
The overall objective of this study is to document Manitoba's First Nations' experience with disability, particularly in terms of equitable access to services. This will be achieved in three dimensions:

1. Development of a population profile of First Nations persons with disabilities, including demographics and disability prevalence, within the wider context of historical changes in socioeconomics and lifestyle.
2. Documentation of the present infrastructure and accessibility of current health care services for Manitoba's First Nations.
3. Ethnographic case studies to document individual and community perceptions of barriers and adaptation to independent living among First Nations people with disabilities.

1.2 THEORETICAL MODEL

The potential obstacles encountered by First Nations persons with disabilities in their pursuit for independent living are depicted in the theoretical framework below (Figure 2). This framework was developed by the researcher after a review of existing documents; preliminary discussions with First Nations persons with disabilities about potential obstacles to independent living; and the personal experiences of the researcher while working in remote First Nations communities in Manitoba as a physiotherapist.

Figure 2
Theoretical Framework



In the centre of the model is the First Nations person with a disability in pursuit of independent living. In this process, the individual is faced not only with needs similar to his or her peers, such as food, shelter, education, and employment, but also obstacles unique to someone living with a disability. These potential obstacles are depicted in the second ring of the model. An individual may have to contend with an environment inaccessible to people with mobility or visual impairments. Mobility aids are generally inappropriate for the rugged terrain of many remote northern communities. Particularly where unemployment rates are high, individuals may not have the financial resources to obtain the assistive devices which would facilitate greater independence. Furthermore, a lack of understanding or acceptance of the issues by those around the individual may preclude financial or even emotional support.

Various factors influence the impact of these barriers on an individual's pursuit for independent living. Variables that have the power to enable or disable the individual's potential for equal participation in the community are found in the outer ring of the model. Legal recognition of an individual's treaty status dictates eligibility for certain benefits otherwise not available. Jurisdictional confusion over accountability in First Nations communities often leaves the person without the formal support services available in other parts of the province. Access to health care services may be restricted by geographical and political boundaries, which for some individuals may necessitate relocation to an urban setting. People may need to rely heavily on their family, peers, and community to make any kind of living arrangement in their community a reality.

CHAPTER TWO: LITERATURE REVIEW

2.1 DEMOGRAPHICS OF DISABILITY

Current data on the size of the population with disabilities stems primarily from self-reported surveys, coupled with investigative observations (United Nations, 1983). The reliability and validity of self-reported prevalence of disease and disability have been questioned in various studies. The accuracy of international disability data has been thrown into doubt by the United Nations (1990). Reporting biases may have occurred where there was a promise of financial, medical or technical aid, resulting in overestimates. Underreporting may have occurred where preschool children or infants have not yet been identified as impaired or disabled. Other inaccuracies may have included incorrect reporting of age; a tendency to exaggerate at advanced ages; the use of proxy respondents; or wilful misrepresentations. Where programme funding and allocation relies on this data, resulting services may not reflect true need.

In an attempt to standardize measurements of disability world-wide, the World Health Organization (WHO) introduced the *International Classification of Impairments, Disabilities and Handicaps* (ICIDH) in 1980. The definitions provide distinctions between the physical and functional components, as well as the obstacles to participation imposed by a given society.

Impairment - any loss or abnormality of psychological, physiological or anatomical structure or function.

Disability - any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

Handicap - A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal, depending on age, sex, social and cultural factors, for that individual.

(World Health Organization, 1980, pp 27-29)

Using the above definitions, the World Health Organization has estimated that 10% of the world's population is disabled (United Nations, 1983). This represents more than 500 million individuals world-wide who are disabled by physical, mental or sensory impairments. It is of note that these definitions are currently under review. The new ICDH-2, *The International Classification of Impairments, Activities and Participation*, is presently undergoing field trials. The expected time of publication is 1999.

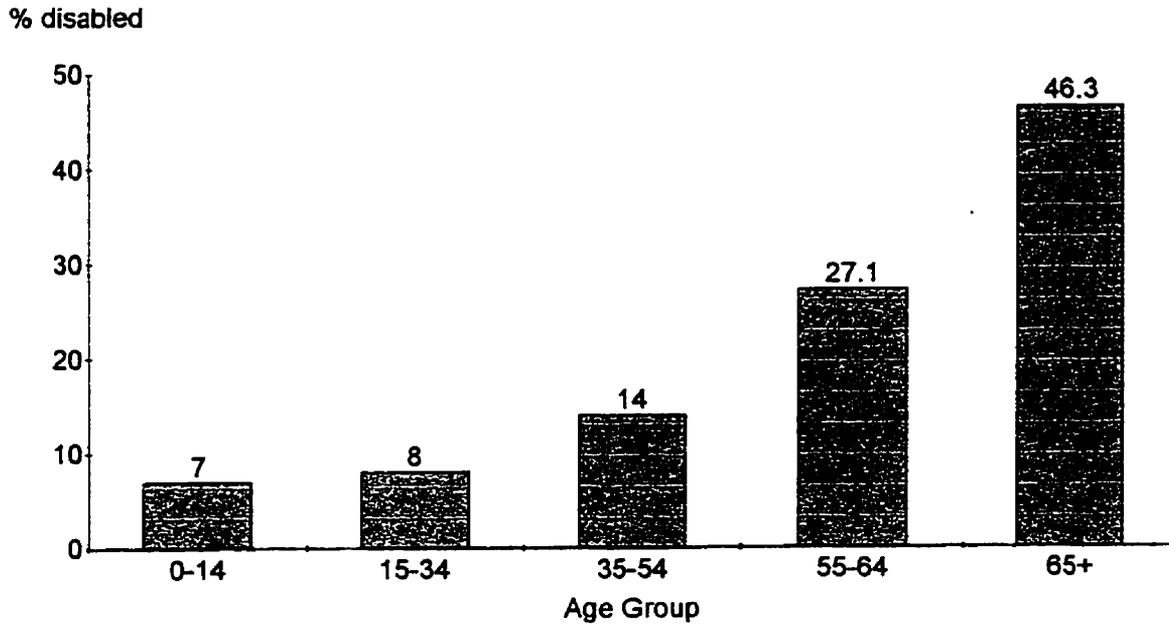
The most recent data collection in Canada has shown a general rise in the prevalence of disabilities. The *Health and Activity Limitation Survey* (HALS) is a post-censal survey conducted by Statistics Canada. It was first conducted following the 1986 Census and then repeated after the 1991 Census. The 1991 HALS had two portions: a household segment and an institutional segment. For operational reasons, the survey excluded residents of penal institutions, correctional facilities, military camps, campgrounds, soup kitchens, merchant and coast guard ships and children's group homes. Aboriginal persons living on reserves were covered separately by the *Aboriginal Peoples Survey* (Statistics Canada, 1992).

In 1991, it was estimated that 4.2 million people or 15.5% of the population had some level of disability (Statistics Canada, 1994c). This is a 3.3% increase from 1986. The rise is attributed to an aging population and a change in survey methodology to include mental health conditions and learning disabilities. Increased reporting as a result of a greater awareness of disability

in society and the barriers that individuals must encounter on a daily basis has also been suggested.

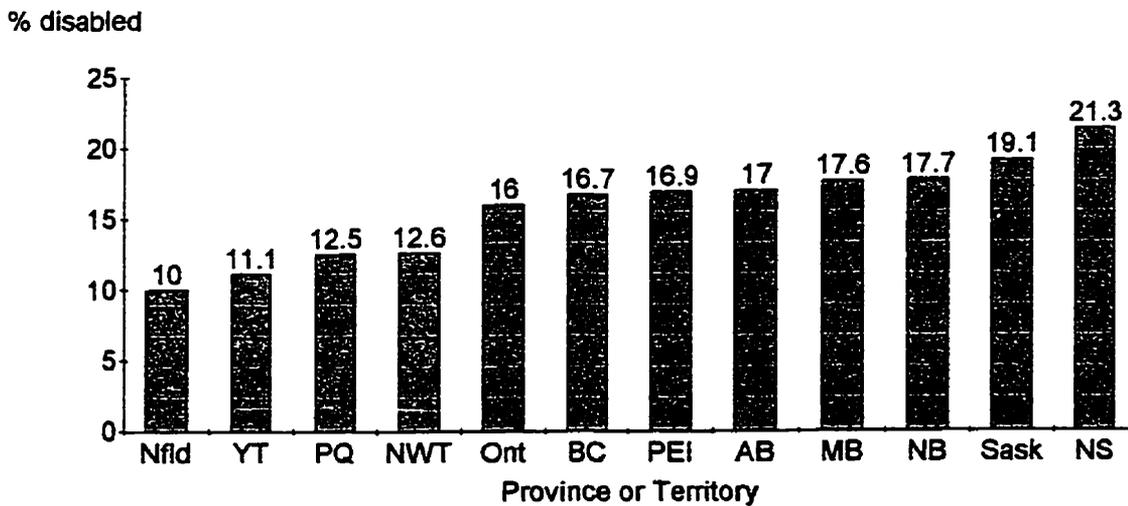
An examination of the Canadian disability data demonstrates certain patterns. As Canadians age, there is an increasing prevalence of disability (Figure 3), with a progressive rise in disability from the youngest age group to the oldest.

Figure 3
Disability Rate by Age
Canada, 1991



(adapted from Statistics Canada, October 13, 1992: p. 3)

Figure 4
Disability Rate by Provinces and Territories
Canada, 1991



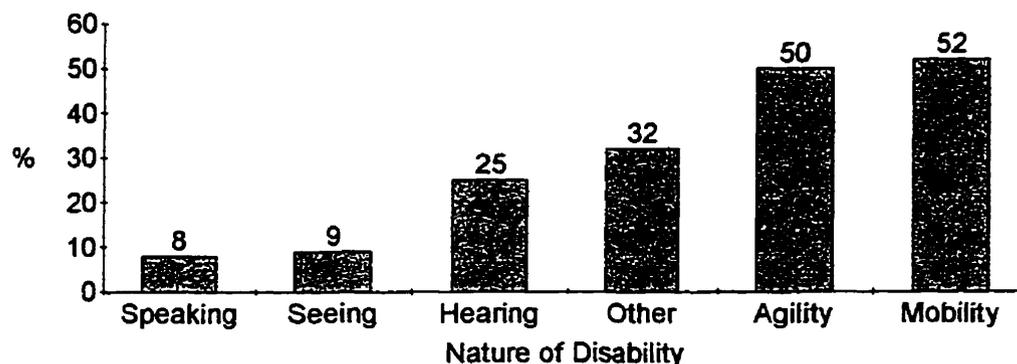
(adapted from Statistics Canada, October 13, 1992: p. 2)

The data also demonstrates regional variation (Figure 4). Newfoundland experiences the lowest rates of reported disability (10%), while nearby Nova Scotia experiences the highest (21.3%). Disability rates in Manitoba (17.6%) straddle these two Canadian extremes.

Women are more likely than men to report a disability, with disability rates of 16% and 15% respectively (Statistics Canada, 1994c: p. vii). This difference has been explained by the longer life expectancy of women compared to men.

Canadians also differ in the nature of the disability. Overall, disabilities in mobility and agility are the most commonly reported (Figure 5).

Figure 5
Nature of Disability
Working Age Population, Canada, 1991



- 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.

(adapted from Statistics Canada, 1994c: p. ix and October 13, 1992: p. 13)

In 1991, one in three working age adults with disabilities reported an intellectual disability, mental health condition, or learning disability (included in the category labelled "other").

From the above data, it is apparent that Canadians experience more than one type of disability. Whether this represents underreporting or overreporting is not known. Nor does the data provide insight into the interaction that may occur between disabilities. By compartmentalizing disabilities into concrete categories, the role that multiple disabilities may play cannot be explored.

The level of education achieved by Canadians with disabilities is increasing, but remains lower than average when compared to the remainder of Canadians. Working age adults (15-64 years old) with disabilities reporting at least some post-secondary education rose from 31% in 1986, to 35% in 1991 (Statistics Canada, 1994c, p. xii). In comparison, 49% of working age Canadians without disabilities had at least some post-secondary education in 1991. The number of working age adults with disabilities who reported a post-secondary certificate or diploma increased from 10% in 1986, to 19% in 1991 (Statistics Canada, 1994c, p. xii). The percentage with a university degree increased slightly from 5% in 1986, to 6% in 1991.

Eighty-two per cent of working age adults with disabilities in 1991 considered their reading and writing skills adequate for their daily needs (Statistics Canada, 1994c, p. xviii); yet Statistics Canada also reported that 32% of Canadians were functionally illiterate in 1990 (Literacy Partners of Manitoba, personal communication, April 9, 1996). Fifty-four per cent of Canadian adults who were found to have difficulty dealing with printed materials reported satisfaction with their reading and writing skills. Eighty-two per cent of those who could use printed materials for limited purposes only, such as finding a

familiar word in a simple text, reported satisfaction with their current literacy level.

The labour force participation rate among working age Canadians with disabilities is increasing but remains lower than the national average. Labour force participation for Canadians with disabilities rose from 48% in 1986, to 56% in 1991 (Statistics Canada, 1994c, p. xi). This compares to a national increase in the labour force participation rate from 78% to 81% in the same time period. The proportion of adults with disabilities not in the labour force because of their disability or health condition decreased from 69% in 1986, to 59% in 1991 (Statistics Canada, 1994c, p. xi). The percentage of working age adults with disabilities who were employed increased from 40% in 1986, to 48% in 1991. A national increase from 70% to 73% was observed for the same time period. Of the 1.1 million Canadians with disabilities who were employed in 1991, 11% believe they were dismissed or were refused employment, promotion, or training in the previous five years because of their disability.

Canadians with disabilities have an average total income lower than their able-bodied counterparts. In 1990, the average income from all sources for working age Canadians with disabilities was \$20,710 (Statistics Canada, 1994c, p. xiii). The average total income for working age Canadians without disabilities was \$26,210. Forty-eight per cent of working age Canadians with disabilities reported an income of less than \$15,000 in 1990, compared to 37% nationally (Statistics Canada, 1994c, p. xiii). In 1990, 30% of working age Canadians with disabilities reported at least one source of income related to their disability, an increase of 7% from 1985. Thirty-three per cent of the same group reported non-reimbursed disability-related expenses in 1990, compared to 37% in 1985. Medications were the most commonly reported expense.

Canadians with disabilities continue to report difficulty with travel, either local or long distance, despite attempts at improving accessible public transportation. In 1991, 5% of working age adults with disabilities were unable to leave their residence because of their condition; this proportion is unchanged from 1986 (Statistics Canada, 1994c, p. xiv). Nine per cent of those adults with disabilities who were able to leave their home required an attendant's assistance to travel locally (Statistics Canada, 1994c, p. xiv). The percentage of working age Canadians with disabilities who were unable to travel long distances because of their condition rose from 14% in 1986, to 16% in 1991. Of the 1.5 million adults with disabilities who travelled long distances in 1991, 16% reported having difficulties while travelling.

The statistics presented here refer to the Canadian population as a whole. The experience of disability among Canada's different subpopulations differs from the national average. Disability rates for Canada's Aboriginal peoples for example are at least double that of the Canadian average. While the type of disability reported does not differ significantly, the socioeconomic characteristics do. The Canadian Aboriginal experience with disability will be explored in Chapter Four.

2.2 DISABILITY RIGHTS AND POLICIES

International, national, and provincial initiatives at improving accessibility for people with disabilities and promoting their full participation have been a direct result of effective lobbying by people with disabilities themselves (DeJong, 1979; Driedger, 1989; Enns, 1981b; French, 1994a). Consumer advocacy groups have exerted sufficient pressure to modify existing regulations and policies both at the international and local levels, in an attempt to ensure their equal rights to full participation. One of the first steps taken by governments has been an attempt at improving data collection and analysis regarding the extent of the number of individuals impacted.

International

The United Nations and the World Health Organization have laid the groundwork for policy initiatives at the international level. The actions taken by the United Nations are based upon three principles set out in the *World Programme of Action* :

1. *Disability Prevention*
2. *Rehabilitation*
3. *Equalization of Opportunities.*

(United Nations, 1983, p. 3)

Strategies have been designed to encourage United Nation member states and organizations concerned with the rights of persons with disabilities, to develop and implement inventive and effective policies, programmes and projects.

The *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (1993) are the most recent initiative by the Member States of the United Nations in the promotion of disabled persons' rights, freedom of choice

and equal opportunities. The Standard Rules seek to adapt the environment and not the individual by emphasizing a person's abilities, not disabilities. The United Nations have strongly encouraged their implementation as a sign of political and moral commitment by individual governments to improve the quality of life of its citizens. The *Standard Rules* are however not legally binding for governments.

National

National initiatives addressing the needs and rights of Canadians with disabilities have developed simultaneously with a growing awareness of the broader determinants of health and the need for health promotion. The *Obstacles* report by the Special Parliamentary Committee on the Disabled and the Handicapped released in 1981, has been heralded as a revolutionary document in the history of the Canadian disability consumer movement. *Obstacles* laid the groundwork for a change in philosophy and a new approach to legislation, program design, and service delivery for Canadians with disabilities (Boschen & Krane, 1992; Enns, 1981b). This report called for the amendment of the *Human Rights Act of Canada* to provide protection for Canadians with disabilities from discrimination in terms of employment, architecture, communication systems, public transportation, and public housing (Enns, 1981b). This philosophy was consistent in nature with the earlier *Lalonde Report* (1975) which was the first political recognition of the broader determinants of health and well-being. It was widely interpreted however, that lifestyle choices were made purely by the individual, thereby absolving society's responsibility in influencing those choices. This was followed by the *Epp Report* (1986) which emphasized a holistic approach to health. Future public policy

makers were encouraged to consider the role of the economic, physical, and social environments on health status and quality of life.

In April of 1982, the *Canadian Charter of Rights and Freedoms* was expanded to include the rights of persons with disabilities. It guarantees equal benefits and protection under the law and prohibits discrimination based on physical or mental disability (Council of Canadians with Disabilities). Amendments to the *Canadian Human Rights Act* in 1983 prohibits discrimination against persons with disabilities in the provision of goods and services, including transportation. But unlike the *Americans with Disabilities Act* passed in 1990 in the United States, there are no provisions for enforcement nor any implementation guidelines. Whether the responsibility of enforcement in Canada lies with the federal government or with the provincial government remains unclear.

As a response to disability advocacy groups, the Canadian Secretary of State published media guide-lines for appropriate terminology for the portrayal of persons with disabilities - *A Way With Words* (Status of Disabled Persons Secretariat). The *Court Challenges Programme* was initiated in 1994 to challenge the *Constitution Act of Canada* or the *Charter of Rights and Freedoms*. Any equality-seeking group is eligible for this federally funded programme, including people with disabilities.

Specific measures to reduce the barriers faced by Canadians with disabilities have been taken in the areas of employment equity, public transportation, and accessibility to public buildings. The *Employment Equity Act* and the *Federal Contractors Program* both came into effect in 1986 (Canadian Council on Rehabilitation and Work [CCRW], 1991). Affirmative action strategies were encouraged for the integration of minority groups into the

workplace, but the lack of mandatory enforcement has made progress slow. By 1989, only 1.6% of employees filled the disability criteria from among the 370 companies under federal Employment Equity legislation (CCRW, 1991). The Canadian Council on Rehabilitation and Work states that these low employment rates are a result of discrimination in the workplace and poor access to educational and training systems in preparation for realistic, gainful employment. They have noted that by the year 2010, 85% of workers entering the workforce will be women, visible minorities, aboriginal people or persons with disabilities.

The *Canadian Jobs Strategy* has provided up to \$10,000 per individual for various types of job accommodation (CCRW, 1991). For over three decades, the *Vocational Rehabilitation of Disabled Persons Act* has provided federal cost-sharing funds to the provinces to facilitate workplace accommodations for job candidates with disabilities. This federal initiative is due to expire in the coming year and its future remains unclear.

Introduction and enforcement of regulations for air travel accessibility have been more successful. Under the *National Transportation Act* of 1987, the National Transportation Agency has the authority to eliminate undue obstacles through regulation. These regulations apply to all transportation services under the authority of the *National Transportation Act* including: air carriers; railways; federally supported ferry services; transportation equipment, facilities, and terminals related to these transportation services. Transport Canada's Policy Statement on Accessible Transportation (1991) states :

Accessible transportation is a right, not a privilege. All Canadians should be able to use Canada's transportation system without impediment. Transport Canada supports fully integrated, barrier-free transportation that accommodates the needs of seniors and persons with disabilities. (p. i)

In terms of the structural environment, barrier-free code requirements do exist in the National and Provincial Building Codes. All federal buildings and properties built after June 1, 1991 were to be accessible by 1995. However, no federal legislation currently exists to enforce the accessibility of public buildings. Public Works Canada produced an *Accessibility Evaluation Guide* to audit federal buildings and act as a guide-line only to upgrade federal property, owned or leased (Public Works Canada, 1992). Claude de Forest, Professor and Executive Director of the Canadian Institute for Barrier-Free Design, has criticized current standards for reflecting the needs of only those with mobility impairments, omitting those of persons with sensory, cognitive and other impairments (de Forest, 1993). He has also stated that current requirements are often inadequate, that codes are only modified every five years, and they fail to explain to designers the principles underlying the requirements. The Canadian Institute for Barrier-Free Design conducts research, collects and disseminates information to professionals and the public-at-large regarding all aspects of the design of accessible buildings and environments. Operating in conjunction with the Faculty of Architecture at the University of Manitoba and the Canadian Paraplegic Association, it is funded privately through the Rick Hansen Man-In-Motion Legacy fund.

In 1991, the federal government announced the National Strategy for the Integration of Persons with Disabilities. It promised \$158 million until 1996, to improve access, economic integration, and participation of Canadians with disabilities. As part of this National Strategy, the Department of Indian Affairs and Northern Development (DIAND) devoted \$5 million to the improvement of coordination and accessibility of existing services for Aboriginal persons with

disabilities living on-reserve. The specific destination of the funds was determined by DIAND, without any direct input by Aboriginal interest groups (Standing Committee on Human Rights and the Status of Disabled Persons, 1993, p.11).

In terms of taxation, Revenue Canada provides a disability tax credit of \$1500 for eligible citizens. Aids and adaptations such as scooters, ramps, and widening doorways are eligible. Half a million Canadians claimed this tax credit in the tax year 1995. Ten thousand people were refused, however, regardless of previous coverage (CBC Radio News, March 11, 1996). Exclusion criteria have been tightened to exclude anyone who can walk more than 50 meters, regardless of falls or terrain. The previous criterion for independent mobility was the ability to walk more than 100 meters.

In research and academic arenas, the federal government participated in the establishment of the Canadian Center on Disability Studies Inc., in conjunction with the University of Manitoba. The federal government granted \$1 million towards the Center's endowment fund in 1995, matched by a \$1 million grant from the provincial government.

Provincial

Policies at Manitoba's provincial level for building codes, public transportation, and employment equity are similar to those set by national standards. Policies aimed at health care services on the other hand are distinctly provincial in origin. Health care falls under the jurisdiction of the provinces as laid out in the *British North America Act* of 1867, later replaced by the *Constitution Act* of 1982 (Taylor, 1987). Although federal cost-sharing mechanisms are in place, the provincial government bears the principal burden

of health care costs. This leaves the federal government powerless to enforce health care programmes in terms of breadth of service.

The *Vulnerable Persons Living With a Mental Disability Act* proclaimed in 1996 is one of Manitoba's most recent political initiatives directed to persons with disabilities. This provincial legislation replaced Part II of the *Mental Health Act*. It is meant to provide for greater empowerment of decision-making by persons recognized as having cognitive or intellectual impairments. External control, which up to this point was held by the Public Trustee, is to be reduced (Jim Derksen, Office of the Vulnerable Persons Commissioner, personal communication, 1996).

Services utilized by people with disabilities such as Home Care are provided through the provincially funded Continuing Care Programme. These support services enable an individual with a disability to remain at home, at a lower cost to the provincial health care system than institutionalization (Manitoba Health, 1992). The implementation and allocation of such programmes remains at the discretion of the provincial health department. Manitoba Health determines the potential beneficiaries of its programmes.

2.3 CONSUMER PERSPECTIVES ON ACCESS

Access to a service is best judged by those who use it, that is, the consumers of the service. The issues raised by consumers with disabilities are based upon the premise that as Canadian citizens, they hold equal rights and responsibilities as do other Canadians (Council of Canadians with Disabilities). These rights are guaranteed under the *Canadian Charter of Rights and Freedoms*. The fact that Canadians with disabilities do not currently enjoy equal access to full community participation is borne out by the results of the *Canadian Health and Activity Limitation Survey* in 1991. Canadians with disabilities do not share equal access to education, employment opportunities, public transportation, or public buildings. Less than average income levels do little to offset the additional living expenses related to a disability.

Barriers to Equal Access

Disability advocacy groups feel that the barriers that society has fabricated limit full integration. The need to completely understand the term "handicap" is stressed by the former Chairperson of the Decade of Disabled Persons Conference Committee, Derek Legge (1993):

Handicap is a function of the relationship between disabled persons and their environment. The *disadvantage* occurs when the person encounters inflexible cultural, physical, procedural or social systems in society. While the disability may be permanent, the handicap is situational. Depending on what is being done by or being asked of the person, it is the existence of barriers that turns an impairment or disability into a handicap. (p. 4)

Individuals with sensory, agility, or mobility impairments are often hindered by environmental obstacles arising from inappropriate architectural designs. Inaccessible buildings, such as those with stairs, narrow doorways, or poor lighting, discriminate against those with disabilities and prevent their full participation. Conventional designs for items such as door handles, light switches, or kitchen and bathroom appliances are often of little use to those individuals with agility or sensory impairments. Inaccessible public transportation in terms of availability or cost limit people with disabilities from taking full advantage of public services and programmes. People with disabilities living in remote, rural areas generally experience even greater difficulty in achieving equal access to limited services. Unequal access to public information through mass media is a common problem. Extra-large print, braille and closed-captioning for those with visual or hearing impairments are but a few examples of alternative modes of communication which exist but are not universally available.

Attitudes

Attitudes toward people with disabilities pose another type of obstacle, which have been described as possibly the greatest barrier of all (Enns, 1981b; Lee & Rodda, 1994). Typical emotional reactions towards people with disabilities include a mixture of fear, ignorance, guilt, pity, discomfort, and discrimination (Ablon, 1990; Enns, 1981b; Roush, 1986). Teachers will not demand effort or expect performance from students they do not think can excel (Enns, 1981b). Employers will not hire applicants they feel cannot do the job.

French has reviewed the literature regarding the attitudes of health care professionals towards people with disabilities (French, 1994b). She states that

while the evidence is inconclusive, there does appear to be a trend towards attitudes similar to the public at large. She suggests that the higher the level of education attained by health care professionals, the more negative an attitude is discernible in their dealings with people with disabilities.

Models of Disability

The traditional medical model which views disability as a chronic illness is felt by many to have perpetuated the paternalism in the health care system (DeJong, 1979; Enns, 1981b; Zola, 1979 & 1982). The "sick role" implies that people with disabilities are no longer responsible for their own affairs, which in turn, often leads to submission and dependency (Boschen & Krane, 1992; DeJong, 1979). Products designed for those with disabilities have been generally marketed through the health care system. This strategy has barred people with disabilities from behaving as independent producers, consumers and citizens (Enns, 1981b). The professions became stronger while the clients became passive, dependent, and economically deprived (Boschen & Krane, 1992; Illich, 1978 as cited in Enns, 1981b).

The medical model is no longer considered relevant to people with long-term disabilities (Boschen & Krane, 1992). The *International Classification for Impairments, Disabilities and Handicaps* (WHO, 1980) went beyond the individualistic concept of disability. Physical impairments may lead to a disability, but it is the environment that limits or handicaps the individual. Structural barriers are often the result of a lack of awareness in society and can be modified where there is political will. Sociomedical models have emerged to replace the traditional medical model with one incorporating this interaction that an individual has with the surrounding social environment (Goldin, 1990; Hahn,

1984; Jette, 1994; Jongbloed & Crichton, 1990; Schlaff, 1993; Verbrugge & Jette, 1994). Society's role in the disablement process is acknowledged and thereby held accountable for disparities in universal accessibility.

Consumer Views on Rehabilitation

The traditional rehabilitation model has been criticized by disability advocacy groups as perpetuating dependency relationships (DeJong, 1979; Zola, 1979). Over the last two decades, there has been a growing call for a broader, more holistic rehabilitation paradigm (DeJong, 1979; Johnson, 1993; Roush, 1986; Short, 1981; Williams, 1987; Wilson et al., 1995). The rehabilitation framework should be shaped by the needs and wants of the person with the disability, not the health care provider.

Very little evidence exists in the rehabilitation literature about consumers' perspectives of their rehabilitation treatment (Johnson, 1993; McCallum, 1990; Wilson et al., 1995). Ros Johnson (1993) attempted to explore British consumers' perceptions of physiotherapy. He interviewed four individuals living with disabilities in the community regarding their recent experience with physiotherapy. Participants used such words as 'demoralizing', 'patronized', 'powerless', 'irrelevant' and 'ignorant' in their descriptions. The overall impression was one of "disenchantment with physiotherapy, its irrelevance to daily life, its failure to ensure understanding and involvement in treatment, and its arrogance in stifling individual autonomy. Physiotherapy was felt to contribute little, if anything, to their current level of independence" (p. 623).

Successful rehabilitation outcomes are only possible with an acknowledgement of the interdependence of psychological and social factors in the physical and functional recovery process.

Aboriginal Voices

Attempts at documentation of the experience of Canada's Aboriginal peoples are few but encouraging (Special Committee on the Disabled and the Handicapped, *Obstacles*, 1981, and *Follow-Up Report: Native Population*, 1982; Standing Committee on Human Rights and the Status of Disabled Persons, *Completing the Circle*, 1993; Royal Commission on Aboriginal Peoples, *The Path to Healing*, 1993). These government sponsored documents reflect upon the daily frustrations faced by Aboriginal people with disabilities. Factors such as unemployment, poverty, social and geographical isolation, and inadequate living conditions are recognized as contributing to an overall sense of poor health and well-being. A series of recommendations addresses the recurrent themes of disability prevention; improved co-ordination of services; accountability; and accessible, culturally sensitive health care. Fragmented programmes with poor consultation and co-ordination were frequently targeted in the report by the Standing Committee on Human Rights and the Status of Disabled Persons.

Because there is no organizational structure for comprehensive program development or management, (community health) services are developed unevenly and delivered inconsistently across the country...the Committee has seen signs that (these inadequacies) are indicative of larger, system-wide, failings and buck-passing between departments.

The Non-Insured Benefits Program attempts to fill the gaps where provincial insured services are unavailable, but this federal program is very limited and its application is often confused and arbitrary.

(Completing the Circle, 1993, pp. 13-14)

Inaccessible houses and community services were brought to the attention of the Royal Commission on Aboriginal Peoples on their Round Table discussions on Aboriginal health and social issues.

All ramps are on the side doors, not main doors, like we are second-class citizens.

There is no escort service or transportation for the blind so all community buildings are inaccessible without help.

Disabled people and their needs are not a priority for Council.

Community is not paved for people in wheelchairs and walkers, not enough attention is paid to services - snow and ice removal.

The accessibility to most services - education, therapy, training - means having to leave home and community to access, leaving behind support structures, family.

(Sinclair, 1993, p. 148)

No medical van or such that could accommodate a wheelchair.

No means. No sidewalks for wheelchairs. No handivan for community use.

I have my own vehicle, however no money for gas, plates and insurance. The store is 55 kilometres away.

(Sinclair, 1993, p. 152)

Themes of isolation and the lack of accessibility to the community and support services are prevalent throughout the personal narratives. Obstacles to community participation range from environmental barriers, to socioeconomic considerations, to a lack of recognition of special needs. Similar issues were introduced in documents produced by the Council of Canadians with Disabilities (CCD), formerly the Coalition of Provincial Organizations of the Handicapped

(COPOH), a disability advocacy organization based in Winnipeg (*Native Consumers Speak Out*, 1987; *Access to the Sweet Grass Trail*, 1993).

Interviewer: What do you feel are the major issues confronting native people with disabilities today?

Response: Barriers and the isolation. The lack of awareness from the Councils and in the community of the disabled.

(COPOH, 1987, p. 7)

Interviewer: What problems and/or obstacles do natives with disabilities have to deal with living up north in isolated reserves or communities?

Response: They are like a forgotten person. They're put into a house where there is no running water, no sanitation, and you have to rely on your family or your friends to haul water back and forth for you. In most cases there are no ramps or ways of getting around, there is no handi-transit system. If you were to get out, the roads, if there are roads - because there are no roads on some reserves, just trails - you still wouldn't have a place to go.

(COPOH, 1987, p. 8)

The physical factors represent only one of the dimensions regarding accessibility. Acknowledgement of special needs for those people with disabilities by the local decision-makers and the available resources at their disposal represent another. These aspects however do not operate in isolation. The wider context of the existing infrastructure of service delivery and accountability in Aboriginal communities must also be considered.

Interviewer: What are some of the problems natives with disabilities face when having to approach either Medical Services or Indian Affairs for services?

Response: The problem is there is no mandate or cut off line on where Indian Affairs takes over on the handicapped. When it is not a medical need, medical services does not become involved, like on the widening of doors, ramps or education and employment. That all automatically becomes a social problem. But then when you go to Indian Affairs, as soon as they see that you are in a wheelchair they automatically think - it is a medical problem. The awareness is not there. They don't realize that it's not a medical problem, it's a social problem.

(COPOH, 1987, p. 8)

The *Report on B.C. Aboriginal People with Disabilities* (1993) stated that the primary message of the Aboriginal people with disabilities in British Columbia was the need for equal recognition by all governments, including First Nations. Affordable and appropriate housing was identified as their first priority. Other concerns raised included poor economic conditions, high unemployment, attitudinal barriers, and inaccessible, culturally inappropriate service delivery .

These documents have provided sufficient evidence, albeit limited, over the last 15 years in support of the issues raised by Aboriginal peoples with disabilities. While it should be recognized that these concerns may not be shared universally, the narratives do provide a basis from which changes may occur. The numerous recommendations made by the various interest groups and committees still await implementation, despite the urgency stressed by consumers. Like other civil rights movements, action will likely only progress as the pressure by effective lobby groups continues to mount.

2.4 INDEPENDENT LIVING

Independent living is a human right that many in industrialized, democratic countries take for granted. For people with disabilities world-wide however, it represents the on-going struggle for equal access to participation in society. In Canada, it is a right guaranteed under the *Charter of Rights and Freedoms*. For those in the United States, it is a right legislated under the *Americans with Disabilities Act* of 1990. The term *independent living* has been described as a philosophy, a social movement and an analytic paradigm (DeJong, 1979).

Independent Living is a process of consciousness raising and empowerment. This process enables disabled people of all ages and with all types of disabilities to achieve equalization of opportunities and full participation in all aspects of society. Disabled people must be in control of this process. Meaningful choices must be available in order to exercise control.

(Disabled Peoples International, 1995)

Independent living represents the freedom to make choices; the freedom to take risks; and the freedom to take control over one's own daily living (Crewe, 1979; Independent Living Resource Centre [ILRC], 1995; Schlaff, 1993). It is a right that many people with disabilities feel they do not currently have (DeJong, 1979; Enns, 1981a; ILRC, 1995; Schlaff, 1993; Zola, 1979). They claim that they have been systematically excluded from the decision-making processes affecting their own lives. The current structure of service delivery and the efforts made by public policy-makers on behalf of people with disabilities have been described as paternalistic, inefficient, and at times, inappropriate (Enns, 1981b; Rosner, 1991; Schlaff, 1993).

People with disabilities world-wide have historically been viewed and treated as passive recipients of the good will of others (Enns, 1981a). They have generally been viewed as "sick", requiring care that only others can provide (DeJong, 1979; Driedger, 1989; Enns, 1981a). Many cultures have traditionally viewed disability as a punishment for bad behaviour, either in this life time or in a previous one (Azevedo, Prater & Lantum, 1991; Goldin, 1990; Mull, 1991). Persons with disabilities have frequently been hidden away from the eyes of society or shunned by its members (Enns, 1981a). Agricultural societies have provided some exception where individuals with disabilities have been incorporated as viable contributors to the socioeconomic status of the community by performing feasible tasks.

Until World War I, people with disabilities were primarily attended to by charitable groups, often with religious affiliations. By helping those more "needy", able-bodied persons could increase their own sense of personal worth and contribution to society (Driedger, 1989; Zola, 1979). After the two World Wars, there emerged a new attitude towards disability. The previous stigmatization associated with disability was dampened by the return of injured war veterans, who were primarily welcomed home as heroes (Driedger, 1989). The polio epidemic of the early fifties and Thalidomide babies of the late fifties and early sixties heightened public awareness of disability. Simultaneous advancements in medical technology and pharmaceutical interventions facilitated a rise in survival rates of victims of disease, violence and accidents (Driedger, 1989). Not only did the overall visibility of people with disabilities in society increase, but an awareness of the possibilities for disability prevention also grew. The public turned to the medical community for guidance, both for illness management as well as social issues. As a response to the social void

that physicians were unable to fill, the first support networks were established. In Canada, organizations were begun in the forties and fifties by parents of disabled children concerned with improving medical services, facilitating recreational activities, and establishing sheltered workshops and segregated housing (Enns, 1981a).

The last three decades in North America have simultaneously witnessed the emergence of a political climate sympathetic to social change. Minority groups such as blacks, women, and indigenous peoples have forged ahead in their struggle for emancipation and self-determination. People with disabilities recognized the opportunity to advance their own quest for liberation from the barriers to full participation in society.

The independent living movement in the United States has resulted in organizational models, networking and advocacy models, recognition of rights and citizen participation (DeJong, 1979; Enns, 1981a). The first Independent Living (IL) Center in Berkeley, California has been heralded as the beginning of the independent living movement in North America. It was created by a group of University of California students with disabilities in 1972, as a result of the proposed discontinuance of their support services. The centre was able to provide attendant services, peer counselling, and reading services for the visually impaired. This philosophy of independence and self-management soon spread throughout the United States and into Canada. It has been likened by some authors as the "last civil rights movement" (Driedger, 1989).

Since the 1970s, people with disabilities have increasingly argued for the right to manage and monitor the quality of the services which they themselves utilize. They wish to be accepted for their abilities, not their disabilities, and to be involved as active partners in decision-making on matters affecting their own

lives. This attitude has led to the development of the "consumer ethic" (Enns, 1981a) in people with disabilities (Boschen & Krane, 1992; DeJong, 1979; Enns, 1981a; Jongbloed & Crichton, 1990; Schlaff, 1993). The outcome has been the proliferation of advocacy groups run *by* disabled people *for* disabled people.

The first organized advocacy groups began to form in Canada in the 1970s, in the provinces of Saskatchewan, Alberta and Manitoba (Boschen & Krane, 1992). By 1976, they formed an umbrella organization, the Coalition of Provincial Organizations of the Handicapped (COPOH) which linked groups across the country. Recently renamed the Council of Canadians with Disabilities (CCD), the key goals of this organization include the creation of a positive image of Canadians with disabilities, the monitoring of federal legislation, and the promotion of policies proposed by people with disabilities (Boschen & Krane, 1992). Disabled Peoples International (DPI), the world's largest umbrella organization of disability advocacy groups, was formed less than a decade later in 1981. It was established in response to the exclusion of people with disabilities from the decision-making process at the 1980 Rehabilitation International World Congress in Winnipeg, Canada (Driedger, 1989). The organization bases its international lobbying efforts on the principles of self-determination, equality, integration and peace.

As the independent living movement grew in Canada, so did the need for resource centres to respond to the diverse needs of people with disabilities. The first Canadian Independent Living Centre was established in Kitchener, Ontario in 1982, followed by Calgary, Québec City and Winnipeg in 1985. The Canadian Association of Independent Living Centres (CAILC) was formed in 1985. With the support of CCD, the role of Canadian Independent Living Centres was defined:

(They exist to) promote and enable the progressive process of disabled citizens taking responsibilities for the development and management of personal and community resources. Centres, while reflecting each community's unique character, will be consumer controlled, cross-disability, non-profit, and promoters of integration and full participation. Essential program components include information and referral peer counselling, advocacy, and service development capacity. (D'Aubin, 1986, as cited in Boschen & Krane, 1992)

Several similarities in the Canadian model of IL centres can be found in its American counterpart. Both are non-profit, consumer controlled, offer peer counselling, and individual advocacy (Boschen & Krane, 1992). The different needs of a rural-based Independent Living centre have been distinguished from its urban counterpart. It is acknowledged that where services are limited, rural IL centres may need to direct more of their efforts at service delivery and development. In contrast, the urban-based IL centres are usually involved in the identification, accessing, and coordination of existing services.

Acknowledgement of the under-representation of certain groups in the independent living movement is apparent. At the 1990 CAILC conference, the goals for the pending decade included the recruitment of otherwise non-participatory minority groups. Such groups included women, persons from visible minorities, homosexuals, persons with AIDS, elderly, and Aboriginal peoples.

Independent Living Movement and First Nations

While the voice for disability advocacy becomes stronger, there has been anecdotal evidence of criticism against the independent living movement for not meeting the unique needs of Aboriginal peoples. The emphasis in the independent living movement on the rights and empowerment of the individual

contrast with the traditional Aboriginal views of the collective good. Whyte and Ingstad (1995) make a distinction between the disability advocacy organizations in northern, industrialized countries from those in southern, less developed countries.

While "equality" for the disabled individual became a powerful tool in the hands of political advocates in the North, it has less relevance where the disabled person is seen primarily as part of a larger whole - the care-giving family. (Ingstad, 1995, p. 190)

Disability advocacy groups in northern industrialized countries, such as Canada, focus their advocacy work on lobbying governments for changes in social policy. In contrast, the analogous organizations in southern, less affluent countries, are directing their energies to meeting more immediate needs, such as providing rehabilitation programmes (Whyte and Ingstad, 1995). Many international programmes view the advancement of overall community development and infrastructure as an advancement of the consumer agenda. Inadequate housing, clean water, and sewage disposal in many First Nations communities have been likened to those of less developed countries. The lack of universal access to the basic necessities of healthy living may preclude advocacy efforts beyond those of immediate needs for many First Nations communities. Nonetheless, an immediate need persists for improvements in the infrastructure affecting persons with a variety of disabilities.

2.5 CROSS-CULTURAL ISSUES IN REHABILITATION AND DISABILITY

Culture has been described as the way people organize their lives in time and space to live successfully in a community (Lowrey, 1987). Helman (1992) depicts culture as a set of implicit and explicit guidelines "which individuals inherit as members of a particular society, and which tells them how to view the world, how to experience it *emotionally*, and how to *behave* in it in relation to other people, to supernatural forces or gods, and to the natural environment" (p. 2-3). Meadows (1991) emphasizes that culture is a learned process, yet dynamic and changing as it responds to changes in the environment and group. Numerous sources in the existing literature have criticized the current health care delivery system for an insensitivity towards the diverse cross-cultural needs of its consumers (French, 1992; Groce & Scheer, 1990; Groce & Zola, 1993; Kleinman, Eisenberg & Good, 1978; Lowrey, 1987; Shah, 1992). Simultaneously, there has been a call for greater cross-cultural research in the health care sector (Patrick, Sittampalam, Somerville, Carter & Bergner, 1985; Soave, 1992; Trevino, 1990).

Only recently has the rehabilitation literature shown a growing recognition of the importance of culture in the delivery and outcome of its services (French, 1992; Jaggi & Bithell, 1995; Jamieson, 1985; Kagawa-Singer, 1994; Leavitt, 1996; Lewis, 1997). Krefting (1991) explains that rehabilitation therapists must recognize the nature of their own background and how it may bias the assessment and treatment of individuals. She feels that the recognition of culture and its role can improve communication, and thereby increase adherence and perceived satisfaction with rehabilitative intervention. Treatment that is more effective, efficient and economical will be inevitable. Mutual respect

and trust are crucial to a satisfactory outcome. Meadows (1991) points out that "health care must not only be given, it must be accepted" (p. 35).

The notion that rehabilitation has a culture of its own is recognized and expounded upon by Lowrey (1987). He compares the components of the culture of rehabilitation with those of alternative cultures. The former stresses individualized services and individual responsibility; is goal and future oriented; is sequential and compartmentalized; relies heavily on the written word; and values scientific and objective evidence. Alternative cultures, on the other hand, may stress community or family services; focus on present reality; value a holistic approach; rely on the spoken word; and respect the supernatural and subjective evidence. The author emphasizes that rehabilitation is an extension of the culture of an industrialized, urban society. This notion has potential implications for the concept of exporting rehabilitation programmes into Canada's northern communities.

The rehabilitative needs of Canada's Aboriginal peoples have been largely ignored in the rehabilitation literature. A review of the years 1990 to 1996 of five popular journals among physiotherapists (*Physiotherapy Canada*, *Physical Therapy (USA)*, *Physiotherapy (UK)*, *Archives of Physical Medicine and Rehabilitation*, *Scandinavian Journal of Rehabilitation Medicine*) was unsuccessful in retrieving any articles pertaining specifically to indigenous populations. The sole example of rehabilitation and Aboriginal peoples found in the professional literature (McRae, *Canadian Journal of Rehabilitation*, 1994) stresses a holistic approach. The author emphasizes that it is the responsibility of the health care provider to familiarize him or herself with the beliefs and values of the individual.

In a recent review of out-reach rehabilitation in Canada, Francis, Lascelles, Cappon, and Brunelli (1993) state that "in the absence of federal or provincial health policy with a clear mandate for out-reach service delivery, out-reach programs have developed primarily in response to informal needs assessments, and local initiatives" (p. 205). No reference to any out-reach services to remote Aboriginal communities is made. In the same review, Peat and Boyce (1993) describe internationally successful community-based rehabilitation programmes as a potential response to the lack of services in rural Canadian communities. International CBR services are geared towards integration with existing primary health services, community development, and/or social welfare systems (p. 283). A major emphasis is placed on consumer-driven design and implementation of the services. The challenges of initiating such programmes in remote parts of Canada, where jurisdictional, cultural and economic issues abound, are not explored in the specific context of Canada's Aboriginal peoples.

A model for community-based rehabilitation in the Baffin region of northern Canada is also presented by Destounis et al (1990). They emphasize the need to utilize resources already existing in the communities, such as Community Health Representatives, augmented by local training programmes. Ingstad (1995) poses several questions concerning the fundamental issues of community-based rehabilitation programmes in areas where resources are scarce. Should attempts be made to reach as many individuals with disabilities as possible with the minimum rehabilitation services? Or should attempts only be made with a "gold standard" of service provision in mind, recognizing the large number of persons who will go unserved? And who decides what is adequate service, or how and by whom it should be delivered? Ingstad states

that the "responses reflect the position of the respondent, the perception of people with disabilities as persons, and the sociocultural context in which choices are made" (p. 189). She warns against the introduction of values concerning disability and rehabilitation into cultures which may not share similar beliefs.

Thus the question of input of public resources in a CBR program becomes not only a question of the allocation of scarce goods and giving priority to one type of need before others, but more a fundamental question of not taking responsibility away from the (extended) family and thereby weakening it as the main source of social security. (Ingstad, 1995, p. 190)

Ingstad also recognizes that cultural perceptions of disability are not static. As the issue of individual rights evolves, so too may the model for services change. This will form the foundation of truly community based programming, rather than merely outreach services. Rehabilitation programmes must reflect the consumer demand for quality of services within the context of realistic resources. Careful consideration must be given to the implementation of paraprofessional models of health care delivery in terms of consumer and provider perceptions of service equity and the political right to equitable services.

The recommendations made by the workshop on Indigenous Peoples and Health concluded that health programs and projects should be based on respect for the culture, values and traditions of indigenous peoples, and acknowledge geographic and social distinctions among communities (PAHO, WHO, CSIH, 1993). An adequate understanding of the sociocultural context of the health of Canada's Aboriginal peoples is necessary for adequate and effective health care delivery, which is sensitive to the consumer perspective (O'Neil, 1989; O'Neil,

Koolage & Kaufert, 1988; Young, 1988). Any proposed projects should be the result of collaboration with community members, and should include community ownership of any research results (Cruikshank, 1993; O'Neil, Kaufert, Kaufert & Koolage, 1993). Health care services must account for individual community perception of need and availability of resources. Rehabilitation programmes designed for First Nations communities must be initiated, implemented and evaluated within this wider context.

CHAPTER THREE: STUDY DESIGN AND METHODOLOGY

An analysis of service delivery to First Nations people living in Manitoba requires both an examination of the existing infrastructure, as well as an investigation into consumer perception of services received. Within the independent living paradigm, Irving Zola (1979) has shown that problems with chronic disability should be reflected in terms of obstacles and social functioning, not inadequacies of physical functioning. Traditional quantitative research typical of medical rehabilitation attempts to explain *how* events took place, but not *why* (Tammivaara & Shepard, 1990). Consequently, microanalytic case studies were chosen within the context of a macroanalysis of service delivery for this project. Individual case studies permit a closer, more detailed examination of the potential barriers and their impact on individuals and their families. A qualitative approach within a quantitative framework was best suited to explore the interaction between the health care system and the individuals it serves.

Community Consultation

Community-based research by its very nature implies community involvement. Regrettably, this has not always been the case for Aboriginal peoples (Royal Commission on Aboriginal Peoples, 1996, p. 325). Research concerning Aboriginal peoples in the past has often been to the exclusion of the people for whom the results may have the largest impact. The Report of the Royal Commission on Aboriginal Peoples (1996) calls for consistent collaboration in all community research initiatives.

In studies located principally in Aboriginal communities, researchers shall establish collaborative procedures to enable

community representatives to participate in the planning, execution and evaluation of research results.

In studies that are carried out in the general community and that are likely to affect particular Aboriginal communities, consultation on planning, execution and evaluation of results shall be sought through appropriate Aboriginal bodies. (p. 326)

In keeping with this approach of community-based research, the consultation process for this project was initiated from the outset. The feasibility of the study concept was initially explored with the Coordinator for the First Nations with Disabilities Project in Manitoba, Ms Doreen Demas. The project aims to increase awareness about disability issues among the province's First Nations. Ms Demas acknowledged that there was indeed a lack of information regarding First Nations people with disabilities and their relationship to rehabilitation. She also participated as one of the key informants in the process of examining the infrastructure of jurisdictional issues and how this infrastructure relates to First Nations. Working in close proximity with the Assembly of Manitoba Chiefs (AMC), Ms Demas advised the researcher that the proposal did not require a formal presentation and approval process by the AMC.

Although the ensuing participant narratives maintain specific individual and community anonymity, access to the community required prior approval from the appropriate tribal council and band council. Information regarding the project was shared with the current Health Coordinator and the Health Councillor of the relevant tribal and band council (Appendix I). After some discussion, their written approval was obtained. It was felt that presentations to the respective councils was not required.

As the selection process of key informants proceeded, potential participants were provided with project information in writing (Appendix II).

Where literacy was a concern, a trained medical interpreter was asked to assist in the process of disseminating information regarding the study. The choice not to participate without penalty and the ability to withdraw at any point during the study were emphasized. Only after the significance and process of the study appeared to be well understood was the informant requested to complete a participant consent form.

While the project was finalized with the thesis committee and the Faculty of Medicine Committee on the Use of Human Subjects in Research, the researcher's employer was also informed. Community Therapy Services Inc., a non-profit agency providing community-based rehabilitation, currently employs the researcher on a part-time basis in the First Nations Therapy Programme, servicing remote northern First Nations communities.

3.1 ETHICAL CONSIDERATIONS

Issues of a non-Aboriginal, able-bodied investigator conducting research pertaining to First Nations people with disabilities were offset by the participation of a local First Nations community involvement from the outset. Consultation with interested parties was ongoing. As well, an invitation was extended to critique the final study report. Dissemination of the study results with the individuals and the community will address any concerns regarding ownership.

Consent was negotiated with the community in the process of community consultation before the study actually commenced. The project description, purpose and significance were discussed and a copy was provided in writing (Appendix I) to representatives of the Assembly of Manitoba Chiefs, the Health Coordinator of the relevant tribal council, and the Health Councillor of the local band council.

Prior to the formalization of any consent agreement with the volunteer participants, the project was discussed thoroughly with the assistance of the interpreter. Written information was provided regarding potential participant expectations and the purpose of the study (Appendix II). Unfortunately, written information was available in English only. The interpreter assured the researcher of the informant's understanding of the issues around consent before any consent form was signed (Appendix III).

The anonymity of the participating individuals and the community was maintained throughout the course of the study. Composite case studies were utilized to mask unique identifiers, in order to ensure individual confidentiality within the confines of a small community. This confidentiality will be equally maintained during any dissemination of the study findings, either in formal presentations or possible publication. The identification of key informants was

made only with their prior approval and where their identification validated a given statement. It should be clearly understood that their perspectives are their own and do not necessarily represent their employer nor the organization for whom they work.

3.2 METHODOLOGY

Quantitative Framework

Data from the 1991 *Aboriginal Peoples' Survey* (APS) carried out by Statistics Canada was used to provide an initial quantitative framework. This post-censal survey targeted persons who reported Aboriginal origins and/or who reported being registered under the *Indian Act* of Canada in the 1991 Census. It was the first such survey attempted by Statistics Canada. The *Aboriginal Peoples Survey* was the result of consultations with national and provincial Aboriginal organizations across Canada; three pilot tests in Métis, Inuit and First Nations communities; and three focus groups with urban dwelling Aboriginal persons. The questionnaire includes such information as housing conditions, health, employment, schooling, mobility and language. The exclusion of residents of hospitals, penitentiaries, hotels and rooming houses for operational reasons (Statistics Canada, 1993d, p. 12) cannot be overlooked when considering the validity of the results. Data was collected through voluntary personal interviews with randomly selected individuals: 91,935 persons from communities with high concentrations of Aboriginal persons, such as reserves; and 43,664 persons from areas or cities with lower concentrations of Aboriginal populations. Overall response rates were 78.5 % (Statistics Canada, 1993d, p. 13).

A total of 273 Aboriginal communities were incompletely enumerated during the process, representing approximately 60,000 people (Statistics Canada, 1994a, p. 8). This included three Manitoba Aboriginal communities during the Census, and seven Manitoba Aboriginal communities during the APS (Statistics Canada, 1994b, p. 171, 173, 175).

The APS data provided the study with a profile of disability prevalence both for Manitoba, as well as for the Canadian population as a whole. Broader determinants of health including housing, education, employment, and environmental sanitation were also considered. These characteristics were then examined in the context of national data available for the same year through the household portion of the *Health and Activity Limitation Survey (HALS)*. These comparisons serve to highlight the disparities in disability prevalence and experiences across Canada.

Two reports in particular were useful in providing a quantitative and thereby comparative context to the issues regarding access to services. *Statistics and Demographics of Physiotherapists and Physiotherapy Practice in Manitoba 1978-1996* (Loveridge, Pereira, McKechnie & Pruden, 1996) was particularly valuable in the evaluation of First Nations access to community rehabilitative programmes in Manitoba. The Report on the *National Consultation on Continuing Care Needs in First Nation Communities* (Health Canada, 1994) augmented the 1991 APS and HALS data regarding support services to First Nations communities.

System Description

The current infrastructure of health and support services to Manitoba's First Nations people with disabilities was explored in two different perspectives. Documents pertaining to service delivery were reviewed, both in the current as well as the historical context. Key informant interviews were then utilized to investigate issues pertaining specifically to Manitoba. These interviews permitted an in-depth exploration into current trends not previously documented. An examination of rehabilitation services, Home Care services, environmental

factors, and assistive devices was used to explore any existing intraprovincial disparities. In this way, the magnitude of the barriers faced by individuals from Manitoba First Nations with disabilities could be studied within the larger context of service availability and delivery.

Key Informant Interviews

The merits of qualitative research in the investigation of rehabilitation outcomes have been recognized only recently within the rehabilitation literature. Over the last five years in particular, the literature has called for qualitative methods to explore the long-term impact of rehabilitation and in the evaluation of rehabilitation programmes (Carpenter, 1997; Jette, 1995; Richardson, 1995; Spencer, 1993; Whiteneck, 1994). In keeping with this trend, a study of the infrastructure of current service delivery to First Nations was determined to be most effectively done using a qualitative approach in combination with a review of relevant documents. Key informant interviews were therefore carried out with a combination of health care planners and providers (Table 1).

**Table 1
Key Informants**

<u>Agency/Organization</u>	<u>Position</u>
Health Care Administrators	
remote Manitoba Band Council	Health Councillor
remote Manitoba Tribal Council	Health Advisor
Community Therapy Services Inc.	Director
First Nations Therapy Programme	Coordinator
Medical Services Branch, Manitoba	Zone Nursing Officer
Health Care Providers	
First Nations Therapy Programme	physiotherapist
Winnipeg Health Sciences Centre	physiotherapists, focus group

The different perspectives that the various informants offered enhance the overall reliability of the study. Open-ended, semi-structured interviews of approximately one and a half hours duration were used in this process. The location of the interview was chosen by the participant, which generally proved to be his or her workplace. Discussions reflected the individual's perceptions of the strengths and weaknesses of present service delivery.

A First Nations advocate working in a liaison role in one of Winnipeg's tertiary hospitals was able to provide further insight into the discontinuity of care from the urban to the rural setting. This informant was also in the notable dual role of former health care provider in a remote First Nations community, as well as former recipient of extensive rehabilitation services. She possessed a distinctive insight into the complexities of care provision for the coordinator, provider, and consumer.

Client Interviews

Qualitative research has the ability to provide the depth of understanding to the human experience not attainable from demographics alone. This holds particularly true in terms of the impact of context and culture upon disease, illness, disability and coping strategies of the individual with an impairment. Ethnography, as one such research method, permits an in-depth description of human behaviour. The purpose of ethnographic inquiry "is to discover and describe human behaviour from the perspective of those persons being studied" (Schmoll, 1987, p. 1895). A descriptive ethnographic study design with open-ended, semi-structured interviews was chosen to investigate the first hand experiences of First Nations people functioning with a disability, the impact of rehabilitation and the return to community living. Kane (1994) states that

the success of rehabilitation can only be measured in terms of the recipient's return to activities in his or her own environment:

The real test of effective treatment is the ability of the client to function in his or her natural environment. It is unacceptable to blame the environment by arguing that it is inadequate to support desired activity. Rehabilitation should be directed toward preparing the client to function in a specified environment, where the benefits of treatment can be assessed. (p. 427)

Four individuals were invited to partake in this component of the study. Individuals were chosen who represented a variety of rehabilitation experiences: head injury, stroke, lower limb amputation, and rheumatoid arthritis.

Three of the participants were recent recipients of rehabilitation services, currently living in the community in which the principal researcher works as a physiotherapist. To optimize recall, persons had to have had contact with rehabilitative services within the last two years. The selection of potential informants was assisted by support workers at the local nursing station, who are residents of the community. With community involvement from the outset, issues of mistrust and reluctance by potential participants appeared to be minimized. Individuals currently receiving physiotherapy from the researcher were not excluded. The professional relationship between the individual and the researcher's role as a health care provider would not be compromised by the outcome of the interview or the individual's choice to participate. This was clearly stated from the outset, as well as documented in the project information prospectus and participant consent form (Appendix II and III).

A fourth participant was invited to share her experiences, although she did not meet the timeline criteria. She was invited to partake nonetheless, due

to her present day activities in health care and First Nations advocacy. Her intricate knowledge of the process of health care service delivery was invaluable.

An interview protocol was used as a guideline (see Appendix IV), but the direction of the discussion remained flexible. The intent of the discussion was twofold. The first purpose was to explore First Nation consumer perceptions of rehabilitation, its long-term relevance and impact. Participants were asked to share their personal experiences of rehabilitation in an environment removed from their own community support networks. They were also asked to comment on potential improvements to the services that they had received.

Secondly, issues pertaining to access to the surrounding community were explored within the context of available support services. Obstacles to full participation in terms of appropriate personal support care, housing, employment and environmental factors were discussed, as well as any impact on family members. A trained medical interpreter working at the local nursing station was available where language barriers were a concern. All three of the community informants chose to utilize this interpreter's services.

3.3 DATA COLLECTION METHODS

The analysis of current service delivery to First Nations people with disabilities incorporated two different types of data collection. Review of historical documents provided a political and quantitative framework for ensuing discussions around equity of service delivery in the context of comparative need around the province.

Semi-structured interviews were then conducted to explore the issues not addressed in existing documents, specifically as related to rehabilitation services for First Nations communities. These were held with key informants familiar with the system delivery, as well as with former recipients of the service. Data was collected during the course of the interviews through the use of a field diary, field notes, and audio recording. The audio-recordings were then transcribed by the principal researcher using MS Works™ software, and by two transcribers using Word Perfect 6.1™ software. Where an interpreter was utilized, only the interpreter's English translation to the researcher was transcribed.

Data Trustworthiness

Issues of "reliability" and "validity" in traditional quantitative scientific inquiry are equally relevant in qualitative methods, but assume new parameters or dimensions by the very nature of the investigation. "External validity" and "generalizability" in quantitative methodology refers to the extent to which the study findings will be representative and can be generalized to similar circumstances and subjects (Creswell, 1994, p. 134). In the qualitative approach however, the intent is not to generalize findings, but rather to present a unique interpretation of the events (p. 159). The equivalent term in qualitative studies is "fittingness" or "transferability". While the issues pursued in this study refer

specifically to the experiences in one particular community in Manitoba, other First Nations communities across Canada may indeed find the results relevant to their own situations.

"Credibility", the qualitative equivalent of "internal validity" refers to the faithful description or interpretation of the human experience (Sandelowski, 1986, p. 30). Issues of both fittingness and credibility were addressed in this study primarily with a method commonly known as "triangulation". By collecting the data in multiple formats from various sources offering different perspectives, there is an assurance that no single data source alone will be taken to represent all perspectives of a particular issue.

The qualitative equivalents for the quantitative terms of "reliability" or "repeatability" are "auditability" or "dependability" (Sandelowski, 1986, p. 33). Sandelowski refers to the "decision trail" of a study that is easily followed by another investigator, who will arrive at similar but not contradictory conclusions. The qualitative data presented here was used to construct such a decision trail, whereby another researcher would arrive at comparable conclusions given the same context and the same time frame.

Subjectivity rather than objectivity is of value in qualitative research when attempting to minimize the distance between the investigator and the respondent and maximize the meaningfulness of the findings. But neutrality of bias in the research results remains crucial. The "confirmability" of qualitative research, referred to as "objectivity" in the quantitative approach, is ensured by the inclusion of actual transcripts in the report. Although the final interpretation of the study findings rest with the investigator, conclusions or recommendations will be consistent with the available data.

3.4 DATA ANALYSIS

Interview data was analyzed within the context of existing documentation supporting the issues of service delivery and obstacles to full participation in society for people living with disabilities. The transcribed data was simultaneously interpreted and coded thematically, looking for both minor and major themes. Relationships between the thematic categories were pursued in a thematic matrix within a narrative format, supported by direct quotations. Individual case studies described within the larger First Nations context were able to provide a glimpse into the experiences of First Nations persons with disabilities. Interpretation of the data was integrated with the literature describing the principles and practice of independent living, the unique issues surrounding First Nations culture, socioeconomic conditions, political trends and health service delivery. Copies of the final report were provided to the individuals and local community involved as an opportunity for negotiation over any potential disagreements with the results as presented.

3.5 LIMITATIONS

Interpretation of the research product is subject to the limitations of most qualitative research studies. While providing a rich resource of information about a particular experience within a particular context, the findings will have limited generalizability. Many of the conditions and circumstances that individuals describe however, are common to many northern First Nations communities. Because each band council is only responsible for local decision-making, each narrative is unique and specific to that given community.

The dual role of the researcher and health care provider must be recognized as a potential bias throughout the study. Performing both roles may have influenced the selection of the sample of respondents from the outset. It may also have inadvertently guided the direction of the various ensuing interviews, as well as the interpretation of the data. Although this familiarity was used intentionally to confront issues of mistrust, potential bias by the respondents towards the investigator may have impacted which aspects of his or her experiences participants chose to share. Despite reassurances to the contrary, clients may have been reluctant to describe negative experiences with services out of fear of reprisal from the investigator in her role as clinician. Also, key informants may have selectively biased their participation in response to the researcher's dual role as "part of the system". Their opinions within the policy context may have been voiced either more critically or less critically than would have been the case with another researcher.

Researcher characteristics such as gender, age, education and non-Aboriginal race cannot be discounted as potential sources of respondent bias. Likewise, the investigator's own personal history and values may have influenced the interview process and selective interpretation of the data.

The extent of the study was also limited by such factors as financial considerations of the researcher, the amount of time required to elicit willing participants and the time involved in transcribing the data.

CHAPTER FOUR: CANADIAN ABORIGINAL HEALTH FRAMEWORK

Full consideration of health service delivery to Canada's First Nations requires an examination of its population health data. These statistics can help to explain the current utilization of health services, as well as help to plan for future needs. With the growing trend across Canada towards decentralization of health services, that is, regionalization, the impact of changes can only be measured if we adequately understand the current system of service delivery. Health services for Canada's Aboriginal peoples must be acknowledged as unique, both in terms of their present delivery, as well as their historical basis.

4.1 POPULATION STATISTICS

The 1991 *Canadian Census* reported over one million people with Aboriginal origins, or 3.7% of the overall population (Statistics Canada, 1993a, p. 1). The *Aboriginal Peoples Survey* found that 626,000 people *identified* with an Aboriginal group. Of those 460,680 people who identified themselves as North American Indian, 64% lived off-reserve (Statistics Canada, 1993a, p. 9). Of those people surveyed, 135,265 individuals identified themselves as Métis, while 36,215 identified themselves as Inuit (Statistics Canada, 1993a, p. 11, 12). Eleven per cent of Manitobans reported Aboriginal origins in 1991.

The population demographics for Canada's indigenous peoples differ markedly from the rest of Canada. Both populations are aging, but the Aboriginal population is and will remain proportionately younger than the Canadian population as a whole. In 1991, 14% of Canadians were between the ages of 5 and 14 (Statistics Canada, 1993a). The proportion of First Nations who fell in this age group was 23%; Métis 23.7%; and Inuit 25.5% (Statistics Canada, 1993a). Population pyramids for Aboriginals have a distinctly wider

base with a smaller proportion of elderly. The proportion of people over the age of 55 in 1991 was 19.7% of the overall Canadian population. In comparison, Aboriginal people in this same age category are far fewer: 7.2% of First Nations, 6.9% of Métis and 6.3% of Inuit fell into this same age category. Currently, the median age of status First Nations is 10 years less than the Canadian median age (Canadian Medical Association [CMA], 1994). The median age gap between Inuit and the national average is 12 years (CMA, 1994). These gaps are projected to continue to rise over the next decade.

4.2 HEALTH CONDITIONS OF ABORIGINAL PEOPLES

Mortality rates alone can not reflect the broad parameters of the overall experience of health and well-being. "Health" has been defined by the World Health Organization (1948) as:

the state of complete physical, mental, and social well-being, and not merely the absence of disease or injury. (as cited in Evans and Stoddart, 1990, p. 1347)

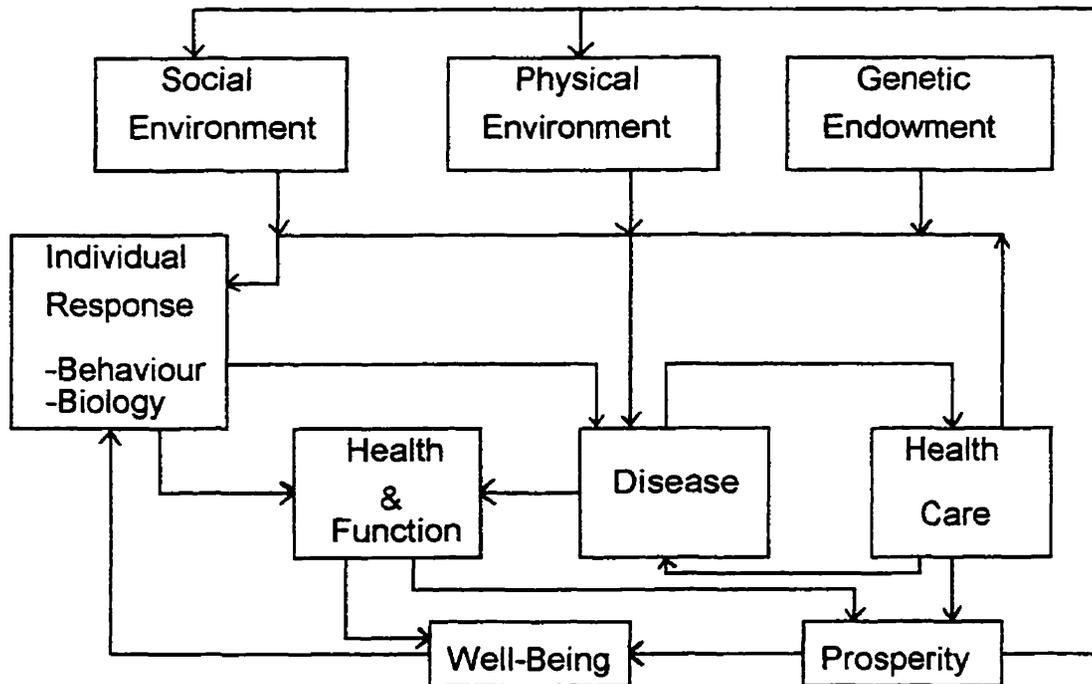
Evans and Stoddart (1990) have developed a new and more elaborate paradigm of the multiple factors influencing health (Figure 6). The authors acknowledge the impact of social, physical and genetic influences not only on the disease process itself, but also indirectly on the individual response. This individual response manifests itself both in terms of behaviour and biology. The authors differentiate "well-being", "health and function" and the biomedical interpretation of "disease". The individual's perception of the absence or presence of health and wellness is not discounted.

Evans, Barer and Marmor (1994) have also described health as the outcome of self-esteem and control. When considering this wider spectrum of health, one must look beyond mere mortality rates. Surveillance over morbidity patterns and mental health are however, considerably more difficult and less reliable.

The magnitude of illness experienced by Canada's Aboriginal population has been well documented (Mao, Morrison, Semenciw & Wigle, 1986; Morrison, Semenciw & Wiggle, 1986; O'Neil, 1995; Waldram, Herring & Young, 1995; Young, 1988). Data regarding the health status of registered First Nations persons living on-reserve is readily available through federal statistics. For those individuals not registered, such as Métis, and those living off-reserve,

health data is non-discernible from provincial statistics. While large gains in health status have been demonstrated over the last few decades, significant discrepancies persist with the remainder of Canada.

Figure 6
Feedback Loop for Human Well-Being



(adapted from Figure 5 in Evans and Stoddart, 1990, p. 1359)

Patterns of Mortality and Morbidity

Manitoba's infant mortality rate (the number of deaths under the age of one) was 7.8 per 1,000 live births in 1990 (Manitoba Health, 1995, p. 22). The infant mortality rate of treaty status Aboriginal children in comparison, averaged 12.4 per 1,000 live births from 1985 to 1989, almost double the provincial average. For Aboriginal children aged 29 days to 14 years, the death rate in 1990 was 142.6 per 100,000, compared to the provincial average of 36.8 per

100,000 (p. 23). The number of suicides among Aboriginal adolescents is presently six times the expected rate for the broader population (p. 27). It is felt that 34% of deaths among Aboriginal children are preventable, including those due to motor vehicle accidents, drowning, suicide and homicide.

The disparity in overall life expectancy at birth of treaty status First Nations compared to Canadians is also significant. Life expectancy for First Nations women is 72.8 years, seven years less than the national average (Waldram, Herring & Young, 1995, p. 66). Life expectancy at birth for First Nations males is 64.5 years, nine years lower than the Canadian average.

Mortality due to infectious diseases continues to decline, yet the overall incidence of infectious diseases remains disproportionately high (CMA, 1994). Many of the diseases can be explained by environmental conditions, such as housing and sanitation, as well as social and lifestyle factors. In 1991, 3% of Aboriginal adults nationally reported having tuberculosis (TB); the Canadian incidence of TB is less than 1% (Statistics Canada, 1993b). In spite of advancements in medicine and public health measures, the incidence of TB among Aboriginal people appears to be on the rise. In 1965, the incidence of TB among treaty First Nations people was 260 new cases per 100,000 per year. By 1990, the rate was up to 267 new cases per 100,000 people (Hoeppner, 1995). A simultaneous increase in the incidence of TB world-wide has been explained by an increase in drug resistance.

According to Waldram, Herring and Young (1995), Aboriginal peoples demonstrate higher hospital admission rates and increased morbidity patterns overall. Rates of male mortality on-reserve are higher than national averages for suicide, cirrhosis of the liver, homicide, cerebral vascular disease and fires. Deaths due to coronary heart disease are similar to national rates, while deaths

due to lung cancer are lower. Rates of female mortality on-reserve are higher for coronary heart disease, suicide, cirrhosis, homicide, cancer of the uterus and cervix, cerebral vascular disease and fires.

4.3 DISABILITY AMONGST ABORIGINAL PEOPLES

The rise in chronic degenerative diseases in the Aboriginal population in recent decades has simultaneously lead to a increase in the prevalence of disabling conditions. This rise has been explained in the literature as related to a change of lifestyle (O'Neil & Postl, 1994; Waldram, Herring & Young, 1995). One key informant, a Health Advisor to a Manitoba Tribal Council describes the changes she has observed:

You know, a long time ago, they used to work hard and they didn't have any problems like that. And now, everybody is fat, everybody takes a car to the store instead of walking.

We had to make a living. If we didn't chop wood, there was no heat in the house. If we didn't go and put nets under the ice in the winter, we wouldn't eat, there was no fish. That was one of my jobs when I was little.

And when my dad built a cabin, we smeared mud and straw between the logs, that's insulation. We didn't know we were working. So that's how we got everything done. And inside, it was all mud floor. We didn't put insulation because the earth breathes. That's what my grandfather told me. The earth breathes and you get circulation from the ground and you have a roof and you make a hole and the pipe goes there. At night you close it, and in the morning you open it up again and everything goes out. And we used to have a clay fireplace and we used to cook there and we'd pass a rope of rabbit snare wire and we'd have the rabbit roasting there. That's what we used to do.

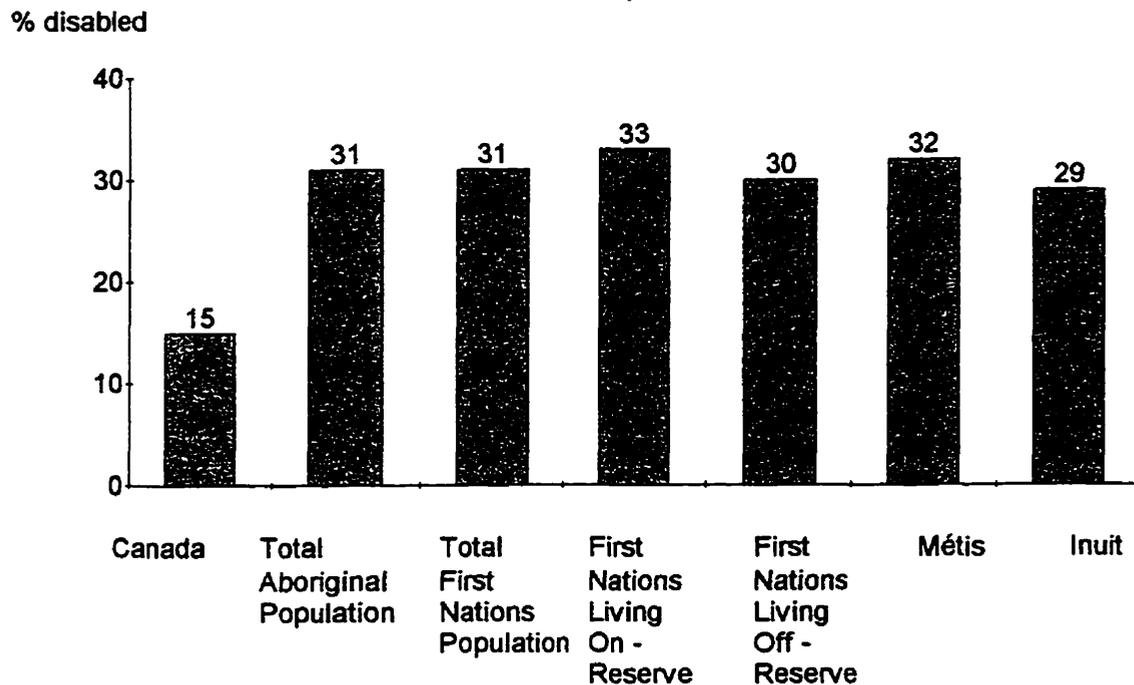
So, now, we don't have those kinds of things. Everybody goes and buys at the store with all these precooked meals with lots of fat and everything. Nobody does anything anymore. So talk about lifestyle changes, the way you eat, the way you do things at home, it's changed.

Subsistence historically required the utilization of all available resources. It was a lifestyle that included all family members, that ensured the transfer of

knowledge from one generation to another. Modernization, with its prepared food and prefabricated housing, has precluded the benefits of an active lifestyle.

Available data on disability rates for Canada's Aboriginal population stems primarily from the *Aboriginal Peoples Survey (APS)* conducted by Statistics Canada in 1991. Details of this survey were discussed in Section 3.1. The proportion of the Canadian Aboriginal population aged fifteen and older who reported a disability in the *APS* was 31%, more than double the national rate (Statistics Canada, 1994a) (Figure 7). The national rate of 15% has been age-adjusted for comparison purposes.

Figure 7
Disability Rate for Aboriginal Adults (aged 15 and over)
Canada, 1991

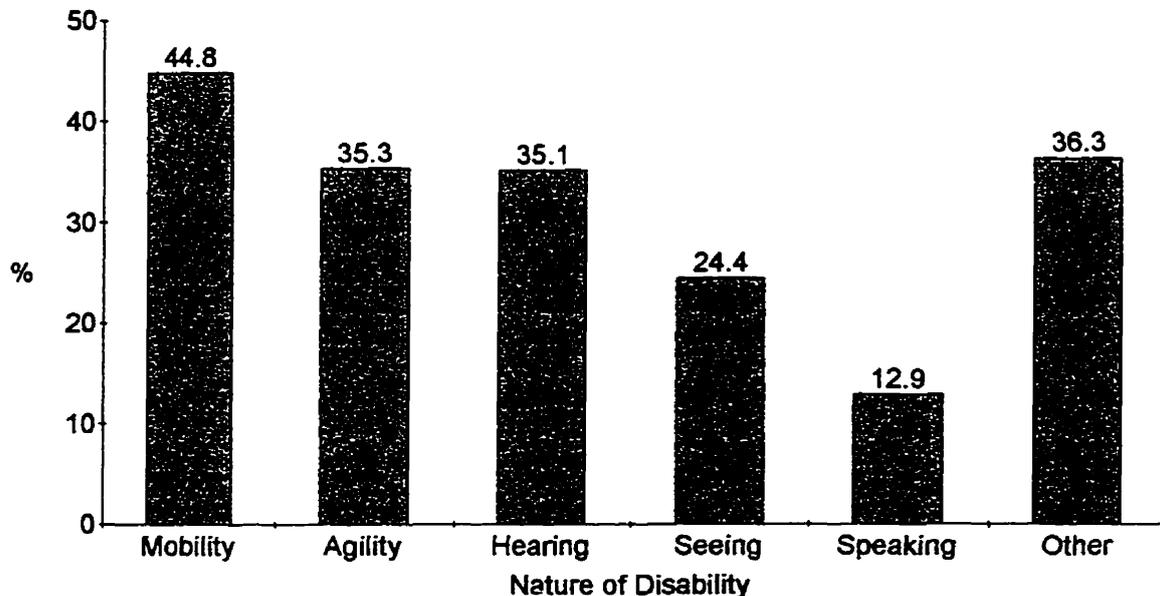


(adapted from Statistics Canada, 1994a)

For those aged 15 to 34, the disability rate was three times higher for Aboriginal peoples than for Canadians overall, 23% and 8% respectively. Among the Aboriginal groups, First Nations persons living on-reserve reported the highest disability rate at 33%. Almost two thirds of the disabilities reported by Aboriginal adults were classified as "mild" in nature on a scale depicting functional loss.

Mobility was the most common type of disability (Figure 8) reported overall by

Figure 8
Nature of Disability, Aboriginal Adults
Canada, 1991



- 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.

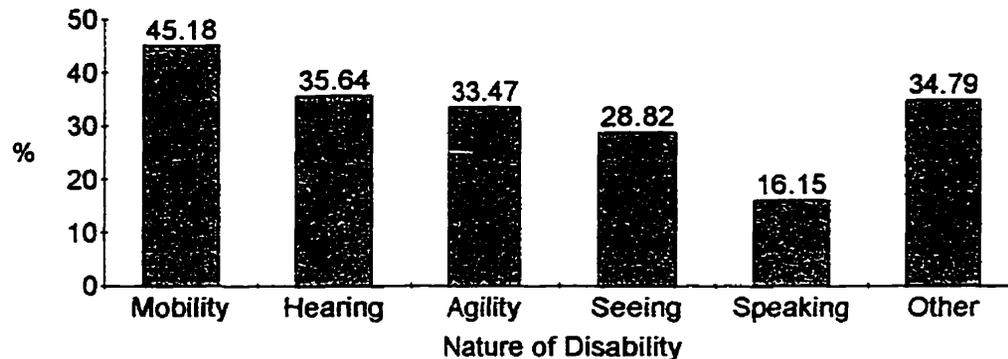
(adapted from Statistics Canada, 1994a)

Aboriginal adults with disabilities (45%), similar to Canadians as a whole. Agility was the second most commonly reported disability (35%), followed by hearing (35%) and seeing (24%) (Statistics Canada, 1994a, p. 4). Fifteen per cent of the Aboriginal respondents reported having arthritis, compared to 14% nationally (Statistics Canada, 1993b). Six per cent reported that they had diabetes, while only 2% of Canadians reported diabetes. This proportion rises to 9% when considering First Nations people living on-reserve. Rates of diabetes among Inuit peoples are similar to Canada as a whole.

Further differences also exist between Aboriginal groups. Mobility was the most common type of limitation reported among First Nations and Métis, followed by agility. In comparison, hearing impairments were the most frequently reported type of disability by Inuit (44%), while ranking only third among First Nations (35%) (Statistics Canada, 1994a, p. 4). These rates are almost double those reported by the rest of Canadians. The higher incidence of hearing loss among Aboriginal peoples has often been attributed to a higher incidence of repeated ear infections (otitis media), environmental factors such as increased noise exposure in overcrowded homes, and a lack of appropriate health services in remote northern regions.

In Manitoba, 18,825 Aboriginal adults reported a disability in 1991. Forty-five per cent, or 8,505 individuals, described their disability as a limitation in mobility (Figure 9). Hearing loss was the second most frequently reported disability in Manitoban Aboriginal people, followed by agility. While the data acknowledges that respondents may report more than one area of limitation, it fails to explore the interaction that may exist among multiple disabilities and how they may influence an individual's lifestyle.

Figure 9
Nature of Disability, Aboriginal Adults
Manitoba, 1991



(adapted from Statistics Canada, 1994b, p. 3)

While self-perceived health and wellness is arguably of more relevance and greater interest to the consumer, one must consider the reliability and validity of any self-reported health questionnaire. In a community health survey conducted in northwestern Ontario from 1973 to 1974 (Young, 1988), approximately 74% of respondents reported "good" health. A follow-up medical examination found that only 3% were "healthy" and free of any clinical abnormality.

The National Aboriginal Network on Disability (NAND) (1990) questioned the findings of the 1986 *Health and Activity Limitation Survey* conducted by Statistics Canada, which concluded that 10% of Aboriginals living on reserve and 13% of those living off reserve experienced a disability. It was identified that disability rates may have been higher had Statistics Canada surveyed Aboriginal people living in institutions; if all reserves had agreed to participate; if the term "disability" had been uniformly understood given the possibility of cultural misconceptions; and if the research instrument had been less complex and redundant. The *Aboriginal Peoples Survey* of 1991 also opted to exclude

residents of hospitals, penitentiaries, hotels and rooming houses. Limitations to the sample of both surveys not only leads to potential inaccuracies in total rates of disability, but also limits the identification of needs of specific subgroups of the Aboriginal population.

4.4 HISTORICAL DEVELOPMENT OF ABORIGINAL HEALTH CARE DELIVERY

The delivery of Aboriginal health care today cannot be thoroughly understood without considering the historical aspects of its origins. "Health" has traditionally been viewed by Aboriginals as integral to all aspects of life. It is a reflection of individual as well as collective relationships to the natural, social and spiritual environment (Speck, 1989). "Well-being" represents a harmonious balance between body, mind and spirit in the individual and in the community. European contact brought not only disharmony into this balance through disputes over control of valuable resources, but also brought the introduction of infectious diseases. The rising threat of mortality among natives helped prompt the negotiation of treaties by Aboriginals in search of securing the survival of their communities. The treaty commissioner at the time, Alexander Morris (1880, reprinted 1991), chronicled this clearly in his reports of the day.

The Indians were apprehensive of their future. They saw the food supply, the buffalo, passing away, and they were anxious and distressed....They desired to be fed. Smallpox had destroyed them by hundreds a few years before, and they dreaded pestilence and famine. (pp. 177-178)

One important factor distinguishing current Aboriginal health care from the rest of Canada is judicial responsibility. The *British North America Act* of 1867 defined the provision of health care for Canadians as a provincial responsibility. It also determined that the "general care of Indians" was a federal responsibility (Speck, 1989). The *Indian Act* of 1876 enforced the federal government's responsibility for issues pertaining to Canada's indigenous population registered under the Act, regardless of any existing treaty. The *BNA Act* was replaced by the *Constitution Act* in 1982, which reaffirmed existing

Aboriginal and treaty rights. Whether the responsibility for Aboriginal health care falls under federal jurisdiction for Aboriginal peoples or provincial jurisdiction for health is the source of much confusion and debate. According to First Nations organizations, it is their treaty right to receive complete access to health care services under federal legislation. They argue that the *medicine chest clause* in Treaty No. 6 signed with the Plains Cree Indians of Alberta and Saskatchewan in 1876 (Appendix V), should be universally acknowledged for all Aboriginal peoples:

That in the event hereafter of the Indians comprised within this Treaty being overtaken by any pestilence, or by a general famine, the Queen...will grant to the Indians assistance of such character and to such extent...necessary and sufficient to relieve the Indians from the calamity that shall have befallen them.

A medicine chest shall be kept at the house of each Indian Agent for the use and benefit of the Indians at the discretion of such Agent. (Morris, 1880, reprinted 1991, pp. 354-355)

The federal government contends that the original intention was essentially the provision of a first aid kit made available to the local indigenous people. The health care services currently provided to the First Nations population by the federal government are said to be merely an act of good will, but not a legal obligation. The First Nations on the other hand, feel that complete access to health care was the underlying intention and that this treaty right pertains to all First Nations equally. The controversial terms of responsibility for First Nations health care continue to be debated, particularly with current negotiations underway for self-government.

Prior to 1945, the control of health services for Aboriginal people fell under the Department of Indian Affairs. The federal Department of National Health and Welfare was established in 1944, and an Indian Health Services Branch was soon developed. The Department underwent restructuring in 1962, creating an amalgamated Medical Services Branch (MSB), essentially responsible for all health care outside provincial jurisdiction.

The *Non-Insured Health Benefits* (NIHBs) programme is administered through the Medical Services Branch (MSB, 1992). These benefits represent certain health-related goods and services which are not provided through provincial or territorial health plans or other third party health insurance. They include certain prescription drugs; dental, chiropractic and podiatry services; traditional healing; medical transportation; medical equipment; orthotics; mobility aids; dentures; hearing aids; and eye glasses. Eligible beneficiaries of NIHBs are those First Nations people registered under the *Indian Act*, or Inuit recognized as such by the Department of Indian and Northern Affairs (p. 3). Persons must also be registered or eligible for registration, under a provincial or territorial health insurance plan. Whether a person resides on or off-reserve has not been a factor.

Health Transfer Initiatives

During the 1970s, the Medical Services Branch began to transfer funds to certain band councils for their own administration of medical transportation and for the salaries of certain health care providers, including nurses and community health representatives (CHRs). The CHRs perform a range of functions varying from public health activities, such as health education to providing limited treatment services in smaller, more remote communities. As band council

employees working in close association with the health centre, CHRs act as a link between the community and the health services (MSB, 1987).

The first systematic inquiry into satisfaction with Aboriginal health care was presented in the *Berger Report* in 1979 (O'Neil, 1995). Community participation in health care and development was formally encouraged by the federal Progressive Conservative government's 1979 *Indian Health Policy*. Aboriginal health was to be approached from its "three pillar" platform:

1. The importance of socioeconomic, cultural and spiritual development to attack the underlying causes of ill health;
2. The reaffirmation of the traditional relationship of the Indian people to the federal government; and
3. The maintenance of an active role by the federal government and the encouragement of Indian participation in the Canadian health system.

(DNHW, 1979, as cited in Young TK, 1984, p. 263)

Community development was considered the first step towards Aboriginal self-determination and empowerment. The *Native Alcohol and Drug Abuse Program* and the *Community Health Demonstration Programme* in 1981, and the *Indian Health Transfer Policy* in 1986 have represented government attempts at what were espoused to be the foundation of future Aboriginal control of health services. The latter policy excluded however, the transfer of non-insured services, the training of health care professionals and para-professionals, funding for band members living off-reserve, and non-Natives living on-reserve. Nor were provisions made for the services of traditional healers. Band chiefs and councils would be accountable to the band membership, as well as to the federal Minister of Health. Ultimate control and decision-making remained with

the federal government (Speck, 1989). Details of future transfer agreements remain under discussion.

Aboriginal Health Care Expenditures

Since the reform of native health policy began in 1979, spending on Aboriginal health care has continued to rise. Since 1979, the Non-Insured Health Benefits (NIHB) programme expenditures have increased from \$36 million to almost \$400 million in 1992 (MSB, memorandum, August 26, 1992). Eligible beneficiaries have increased from 325,000 to 557,000 persons in the same time period. It is estimated that half of the Medical Services budget goes towards NIHB (Paul F. Cochrane, Assistant Deputy Minister of Medical Services Branch, 1996). Expenditures in the province of Manitoba have risen from \$19 million in 1985-86 (55,275 eligible beneficiaries) to \$54 million in 1991-92 (79,000 eligible beneficiaries) (Cochrane, 1996). Of an apparent \$14 million deficit, \$12 million is from the medical transportation program alone (Assembly of Manitoba Chiefs [AMC] Health Secretariat & Manitoba Keewatinowi Okimakanak [MKO], Briefing Note, December 6, 1997, p. 4).

Medical Services Branch has explained the rise in costs by higher fees, rising prices, increases in the number of people eligible for benefits and increased knowledge of benefits available (MSB, memorandum, August 26, 1992).

4.5 SPECIAL PREMEDICAL STUDIES PROGRAMME

Current health care delivery to Canada's Aboriginal peoples has been criticized for cultural insensitivity and for poor continuity of care. Services have historically been provided by non-Aboriginal health care providers in the community or in a foreign hospital setting. High turn-over rates of health care staff working in rural, isolated communities have precluded establishment of a feeling of trust in many caregiver relationships. A popular approach to this problem has been to increase the recruitment of health care professionals of Aboriginal background. It is felt that Aboriginal health care providers who share similar health experiences, values and beliefs can provide services in a more culturally sensitive framework. Furthermore, it is hoped that Aboriginal health care workers would choose to pursue permanent employment in their home communities.

With this in mind, the University of Manitoba established its Special Premedical Studies Programme (SPSP) for Aboriginal persons in 1979. Its goal is to prepare Aboriginal students for admission to one of the health faculties, including medicine, dentistry, degree nursing, and medical rehabilitation. The programme is funded by the Province of Manitoba, through the Department of Manitoba Education and Training. All those students registered under the *Indian Act* have their living allowances, books and tuition paid for by the Department of Indian Affairs and the Manitoba Indian Bands.

Through this access programme, six individuals have graduated from the School of Medical Rehabilitation at the University of Manitoba until 1996: four physiotherapists and two occupational therapists. There are currently four students in the programme: two in occupational therapy and two in physiotherapy.

Criticism of the SPSP programme has concentrated on the lack of employment opportunities for rehabilitation therapists in Aboriginal communities after graduation (Dr. Carla Stephens, SPSP Coordinator, personal communication, March, 1997). Either Medical Services will not fund the service in a particular Aboriginal community or Manitoba Health feels it is outside their jurisdiction. Furthermore, existing positions may already be held by a non-native individual, protected by the employee's bargaining unit. Where positions are available, Aboriginal health care providers may find themselves in an awkward dilemma. Returning service to their community may be fuelled as much by obligation as by desire. Should they choose to work in a non-Aboriginal community, possibly under a different pay structure, they risk being criticised for exercising their professional options. Similar to their non-Aboriginal counterparts, Aboriginal persons born and raised in an urban setting may feel no obligation or desire at all to work in a rural, possibly isolated community. It should not be assumed therefore, that the mere recruitment of Aboriginal health care workers will necessarily produce greater numbers of Aboriginal persons choosing to work in Aboriginal communities. This strategy may take many more years before a noticeable outcome is evident at the community level.

4.6 CURRENT PATTERNS OF SERVICE DELIVERY TO ABORIGINAL PEOPLE WITH DISABILITIES

Service delivery and availability for Aboriginal people with disabilities can differ markedly from those of other Canadians. Access to services hinges upon location, while benefits vary according to treaty status. Despite the federal government's involvement in Aboriginal health and social issues, disparities exist in the extent of services between and within the provinces and territories. Many existing programmes promoting the equal participation of people with disabilities in society are provincial initiatives and are thus unavailable on-reserve. Those existing services on-reserve are provided at the discretion of the Medical Services Branch and/or local band councils.

Medical Services Branch in the Manitoba region is divided into north and south zones, roughly analogous to the fifty-third parallel. Each zone has its own director, assistant director, and three zone nursing officers. The zone directors answer to the regional director for Manitoba, who in turn answers to the assistant deputy minister. This person is accountable to the deputy minister, who is accountable to the federal Minister of Health. Medical Services Branch (MSB) runs two federal hospitals in the province: Norway House and Percy Moore, in Hodgson. The six federal personal care homes in Manitoba are under the mandate of the Department of Indian Affairs and Northern Development (DIAND). These homes are found in the communities of The Pas and Norway House in the north zone and Peguis, Fisher River, Sioux Valley and Fort Alexander in the south zone.

Public health services for Aboriginal peoples provided through Medical Services Branch may include health promotion programmes, emergency health care, occupational and environmental health, immunization, communicable disease services and pre- and post-natal care (MSB, 1992, p. 7). Health

services in isolated and remote communities are generally provided in nursing stations. Medical Services Branch runs 18 nursing stations in Manitoba, where it employs its own nurses (Cochrane, 1996). Two to six nursing staff reside on-site, depending on the size and established needs of the community. Physician and other specialty health services are flown in on a transient basis. Services include a community health programme and primary health care. Obstetrical services are limited to prenatal care and women are sent out "for confinement" at 38 weeks gestation. Communities have no access to the provincial Home Care services, making home supports scarce. Medical Services Branch also runs four health stations, analogous to "satellite nursing stations" (Cochrane, 1996). These units provide similar services to those provided in nursing stations, but nurses do not reside permanently on-site. Emergency services are provided by the nearest nursing station.

There are fifteen health centres run by Medical Services Branch in Manitoba (Cochrane, 1996). These are generally located in the less isolated communities. Emergency care is available if required, but the primary focus is community and public health programmes. They do not have the capacity to follow up on early hospital discharges, or for home nursing care. A community health nurse resides on-site and is generally employed by the local First Nation band council (Cathy McGuire, then South Zone Nursing Officer, personal communication, September 20, 1996). Similar services to the health centres are offered in the twenty-one health offices where, however, no community health nurse resides on-site (Cochrane, 1996). Here the Community Health Representatives (CHRs) manage the day-to-day community health programmes. A Zone Nursing Officer explains the mandate of Medical Services as follows:

We have the mandate, under the federal-provincial agreement of 1964, to provide the primary care. Under the (*Constitution Act* of 1982), the province has the mandate for treatment. All that Medical Services Branch has is the mandate for prevention. But under the federal-provincial agreement of 1964, in certain communities we have the mandate for the primary care, for the treatment as well.

This position precludes the federal government's role in the extension of services in health centres or health offices to meet the changing needs of early and more complex hospital discharges. Hospitals must either accept delayed discharges, or families from First Nations communities are obliged to bear the burden of increased caregiving at home, without the supports offered to their provincial counterparts.

Persons from First Nations communities who are required to travel off-reserve for medical appointments, have all travel expenses paid by the Non-Insured Health Benefits. Conversely, Aboriginal peoples residing off-reserve, regardless of treaty status, are expected to utilize provincial services. For those individuals from First Nations who require relocation from reserves to the city for medical reasons, the ensuing jurisdictional battles can be frustrating for both the individual and the care coordinator. A key informant who works as both First Nations advocate and case co-ordinator explains:

We always get the federal and provincial jurisdictional problems. Like dialysis patients... when they come down, they have to stay in the city because there's no dialysis units up north. So as soon as they become residents of Winnipeg, they lose all of their eligibility for medical boarding homes and also transportation, which makes it very hard for them. We keep arguing to them, it's not their fault that they're down here. They're down here because they have to relocate because they have to be on dialysis three times a week. Then, you ask for help from the provincial or the municipal governments, and they say it's a federal responsibility.

Native Liaison Services

In recognition of the large proportion of Aboriginal people in their patient populations, the two tertiary hospitals in Winnipeg offer Aboriginal health interpreters or Native Liaison Services. Kaufert and Putsch (1997) describe these individuals as not only language interpreters, but also as patient advocates and cultural consultants. For those individuals coming from northern communities, who speak no English and who may be intimidated by unfamiliar western medical hospital practices, these services offer a cross-cultural link. Although their own language dialect and specific cultural background and health beliefs may be different from those of the assigned interpreter, it is nonetheless an attempt at reducing cultural barriers in the health care setting. A physiotherapist at Winnipeg's Health Sciences Centre expresses how pleased she is with the available interpreter services:

But as far as the interpreters..., I think it's an excellent service. We've had rehab patients come in and they understand, well, no English, because they've come from a northern community... The interpreter will say what time they're going to be down, and they're there, on the dot, everyday. And they're there through the whole programme. Every single day that they're here, they're interpreting. I think we have excellent services.

Alternatively, she also reports the use of other patients for translating and information gathering:

The Native Services here will usually always have an interpreter down in the department at some point in time. Plus the patients are really good. If you have a really good patient, you know you just need a question answered, a lot of them will interpret for one another. But not for the assessment. You get an interpreter. The peer kind of help is good as well. A lot of other people have been to that reserve, or come from that reserve, and they can give you

more of an idea. If someone only speaks Cree, Sauteaux, or whatever.

While some of the information gathering may seem quite trivial to the health care provider and peer involvement certainly has its benefits, the accessibility of interpreting services in all situations seems questionable.

In contrast to the therapist's perception, interviews conducted with recipients of rehabilitation services within the previous two years portrayed different experiences. Two of three individuals could not recall ever meeting any Native Services Liaison worker. These two individuals were receiving in-patient rehabilitation following a stroke and a head injury, for three and a half months and four months respectively. Whether this is explained by poor recall, or a lack of common-language liaison worker, or a decision by the health care provider not to utilize the services, is unclear.

Interviewer: Did somebody from Native Services Liaison, did they come and translate a lot for her? Were there people around to access?

Response (through Interpreter): No. I guess only their kids.

Costs

Personal financial costs are another important component in the ability to access the assistance and technology necessary in pursuing independent living. Given the high unemployment rate among Aboriginal peoples, two and one-half times the national rate in 1991 (Statistics Canada, 1993c), the affordability of services, aids and adaptations is a significant factor. Eligibility for benefits is determined by treaty status. Non-status Aboriginals receive no special benefits beyond those provided by provincial health plans. Third party insurance plans

such as Workers' Compensation and Autopac exist, but benefits are generally limited and often require lengthy medical justification. Aboriginal persons who are registered under the *Indian Act* have access to the Non-Insured Health Benefits (NIHBs) programme through Medical Services Branch. Medical Services does not, however, feel obliged to duplicate funding mechanisms for programmes normally covered by the provincial health care system. To this end, MSB has made recent moves to shift increasing responsibility for Aboriginal health services to the provinces. It has been stated that " it is not the intent of the NIHB Program to create a two-tiered health care system" (Manitoba Regional NIHB Manager, MSB, Information Bulletin No. 14, October 30, 1995). However, provincial regulations and provincial resource allocation have not reflected a change in this policy to date. Critics of Medical Services feel that this is merely a means of cost-cutting before the transfer of health care funds to First Nations control.

The barriers to independent living for First Nations people with disabilities in small communities are sometimes insurmountable. Costs, attitudes, environmental issues, and access to services will often dictate where an individual and his or her family will choose to reside. A key informant working as a First Nations advocate and liaison in one of Winnipeg's tertiary hospitals describes a common scenario:

So the building designs, the infrastructure in the communities and attitudes, you know, costs... a lot of barriers for these people to return up north to live independently after they get rehab. Then if they do go back, then they're fighting for services. Most of them end up staying here in Winnipeg or in Thompson. If they want to continue living as independently as they can, then they have to stay in a bigger centre. And it's a big sacrifice for a lot of them, because they want to be near their families and relatives. I guess until the community leaders decide what's best for these people...

well, they know what's best for these people, but once they start making things more accessible, then maybe more people with disabilities will live on the reserve.

Pauline Wood Steiman, Health Advisor to the Island Lake Tribal Council, estimates that between five and six hundred people from the Island Lake Region are living in Winnipeg for medical reasons (personal communication, February 9, 1997). Approximately seven thousand people reside in the four communities of the Island Lake area, accessible by winter road only for approximately two months a year. Boat and skidoo are the main means of local transportation. Commuting to outside communities is only possible by airplane. Local roads are made of dirt and gravel and sidewalks do not exist. Health services are provided through band employed community health representatives and in local nursing stations, staffed full-time by nurses. Physician services and other health care specialists are available on a transient basis. Improvements in the provision and coordination of services are crucial if Aboriginal people with disabilities are to be given the opportunity to remain in their communities. An examination of rehabilitation services, home care services, environmental issues, and special devices, demonstrates how the present system operates for Aboriginal peoples in Manitoba. It also emphasizes the magnitude of the barriers that Aboriginal persons with disabilities must overcome in their battle for the right to independent living.

CHAPTER FIVE: REHABILITATION SERVICES FOR FIRST NATIONS

Rehabilitation has been defined as "the restoration of optimal levels of physical, psychological and social ability within the needs and desires of the individual and his or her family" (Andrews, 1987 as cited in Tyson, 1995, p. 430). The United Nations' *World Programme of Action Concerning Disabled Persons* (1983) describes rehabilitation as a

goal-oriented and time-limited process aimed at enabling an impaired person to reach an optimum mental, physical and/or social functional level, thus providing her or him with the tools to change her or his own life. It can involve measures intended to compensate for a loss of function or a functional limitation (for example by technical aids) and other measures intended to facilitate social adjustment or readjustment. (p.3)

Traditionally, the rehabilitation team is comprised of physiotherapists, occupational and speech therapists, working in conjunction with a physician, nurse, psychologist, dietician, social worker and other health care providers as required. Together with the client, interventions are pursued to assist the individual's return to as active and independent a lifestyle as possible. This professional team approach was first developed both in Canada and the United States following World War II, in response to the numerous servicemen returning home with disabilities (Boschen & Krane, 1992).

Currently, the services of rehabilitation therapists are funded by the provincial health plan to all Manitobans and are generally provided in hospital settings. Third party insurance plans generally provide a limited amount of coverage, making therapy in private clinics an alternative to lengthy hospital out-patient waiting lists. While readily available in urban areas, services in rural

parts of Manitoba exist on a much more limited basis. The extent of services are determined primarily by resources, both fiscal and human. A severe shortage of speech therapists in Manitoba makes their services virtually inaccessible in rural areas.

People belonging to First Nations, who live in urban settings or off reserve can avail themselves of all provincial rehabilitation programmes under Manitoba Health Services. For those First Nations persons living on-reserve, access to rehabilitation services varies. Where available locally on reserve, services are limited and vary between communities in terms of quantity and type of therapy offered.

Flexibility in First Nation Service Provision

While rehabilitation services in First Nations communities are limited, it must be recognized that existing services have certain advantages over their provincial counter-parts in terms of flexibility. For example, under Manitoba's *Physiotherapy Act* of 1981, physiotherapists are required to practise "in consultation with the patient's physician" (Article I, Section 2.1 - 2.2). This means that the physician, or dentist, must be aware of and be informed, preferably in writing, of physiotherapy interventions. In busy urban-based practice, the public only has direct immediate access to physiotherapy in private clinics. To gain entry into the publicly-funded system offered in local hospitals, a written referral by the client's physician is generally required. That is, institutional policies dictate access.

Alternatively, in remote First Nation communities, there appears to be greater flexibility in referral patterns. Members of the community are encouraged to seek the assessment of a nurse practitioner first, essentially for

screening, before seeing any specialist. This is particularly valuable in high volume clinics where resources must be managed carefully. Where scheduling permits, however, the public does have direct access to some publicly funded services which their urban counterparts do not share. An individual can consult a physiotherapist for instance, merely by requesting an appointment. Formal referrals by a client's physician are not mandatory. In community health centers or nursing stations where the health care team works in close proximity, patient documentation of clinical findings and intervention strategies are shared and readily accessible. Communication between team members is thus maintained either verbally or through the client's chart. Clients can feel confident that their health status is reviewed and relevant information is shared between the care providers.

Not only may access to available health services be more flexible in small communities, but the practitioners may find themselves less bound by traditional professional boundaries. This may provide the clinician with a more rewarding practice experience. In the case of physiotherapists, clinicians may find themselves taking on activities normally delegated to the occupational therapist in an urban-based practice. Such activities may include the ordering of wheelchairs, the fabrication of resting splints for painful joints, or the assessment of activities of daily living. Where occupational therapy services are not available, the physiotherapist is left to tackle these tasks and make referrals where necessary.

The clinician also has the flexibility of time management. In many busy clinical settings, therapists do not have the opportunity to monitor individuals with multiple chronic health problems over the long-term. Therapists are expected to address the problem at hand, in as short a time frame as possible,

and discharge the case. Alternatively, in First Nations practice, therapists have the flexibility to monitor clients with chronic health problems over as long a time frame as they deem beneficial. The only restraint to the clinician's practice style is volume of referrals.

Paediatrics

Special paediatric programmes offer physiotherapy, occupational and speech therapies to children with special needs, both pre-schoolers as well as those attending school. *School Therapy Services* offers fee-for-service physiotherapy and occupational therapy consultation to various school boards, including Winnipeg, Brandon, Portage, and Frontier School Division. School visits are made several times a year, depending on need and access by the therapist. The *Society for Manitobans with Disabilities* provides therapy services to pre-schoolers within the city of Winnipeg.

Mobile Therapy Services is a rural outreach programme primarily for pre-schoolers. It is run out of the Rehabilitation Centre for Children, under the auspices of the provincial Department of Family Services, *Children's Special Services*. Their geographical catchment area extends across the province, but they do not duplicate existing outreach services. Community visits are made once every four to eight weeks, for one to four days. Areas where they serve include communities 90 kilometres beyond Winnipeg; 45 kilometres beyond Brandon; Dauphin; Central Manitoba; North and South Eastman; Westman; The Pas; Flin Flon; northern Interlake; Swan River; and the northern boundary of Thompson. *Southcentral Regional Therapy Services* based in Morden serve Southcentral Manitoba.

Paediatric services on-reserve are only sparsely available. *School Therapy Services* do provide occupational and physical therapy consultation services to five First Nations communities under the auspices of the Frontier School Division. These communities include Norway House and Berens River, four times a year; Crosslake and Hollow Water, three times a year; and Waterhen two times a year. The Frontier School Division also offers speech therapy services on a limited basis to such communities as Cross Lake and Norway House. *Mobile Therapy Services* do not provide any services on reserve. The Frontier School Division contracts the services of a speech-language pathologist for several of its schools, including those located in the First Nations communities of Norway House and Cross Lake.

In-Home Visits

Physical and occupational therapists are available for assessments and limited treatments in private residences, guest homes and nursing homes, as part of Manitoba's Continuing Care programme. Community-based therapy services have been provided in the province since the 1950s. *Community Therapy Services Inc.*, a private, non-profit agency, began as a Therapy Division of the Arthritis Society. After an interim period as a Division of the Sanatorium Board of Manitoba, it became incorporated in 1989. It also offers home therapy services through Family Services and Veterans Affairs Canada.

Rehabilitation services normally provided through the Office of Continuing Care are not available on-reserve. This is related to Manitoba Health's position that in-home visits form part of the provincial home care programme which is not mandated to operate on-reserve. Manitoba Health feels that home support services on-reserve are a federal responsibility, not provincial. Any

rehabilitation services available locally must therefore be provided at the local health centre or nursing station, and not in the home as is permitted throughout the rest of the province.

Travel

Individuals from rural Manitoba, who require extensive rehabilitation, for example following limb amputation, stroke, joint replacement, or spinal injury, must travel to larger health care settings, usually in Brandon or Winnipeg. The *Northern Patient Transportation Programme* offers financial subsidies to Manitobans from northern communities travelling to tertiary and secondary health centres for medical services not available locally (John MacDonald, Manitoba Health Emergency Services, personal communication, November 6, 1997). Emergency transportation costs are covered in full, while a \$50.00 deductible fee is charged for transportation for elective procedures. The costs of accommodation and meals for escorts are covered for the first day only during medical emergencies. Accommodation during elective procedures are the responsibility of the claimant. The budget for this programme was transferred to the new Regional Health Authorities in April, 1997.

Persons living on-reserve but near provincial hospitals which offer rehabilitation may utilize off-reserve provincial programmes. For some communities, this may represent a three to four hour drive, or a short airplane ride away. Travel costs related to medical appointments for those residing on-reserve are covered under the Non-Insured Health Benefits (NIHB) programme with prior authorization. Those First Nations persons whose principal residence is off-reserve, regardless of treaty status, are ineligible to have their travel costs

for medical appointments covered by NIHB. They are, however, free to apply for the regional *Northern Patient Transportation Programme* travel subsidy.

Similar to other Manitobans living in rural areas, individuals from First Nations who require more extensive rehabilitation must travel to larger health care settings, usually in the city. While medical transportation may be covered by NIHB for the person in question, the programme will only pay for a family escort for those under the age of 18. Exceptions are sometimes made for life threatening situations, where a family member is allowed to accompany an adult on compassionate grounds. Rehabilitation, however, is generally viewed as elective and not as a medical emergency. Intensive rehabilitation is thus carried out for the most part in settings which limit participation and support from family and community networks.

Role of Family

Rehabilitation incorporates the family in terms of emotional acceptance of a disability and its long-term management. The isolation of an individual from the support that family members can offer can impact the success of rehabilitation. The United Nation's *World Programme of Action Concerning Disabled Persons* (1983) states :

Important resources for rehabilitation exist in the families of disabled persons and in their communities. In helping disabled persons, every effort should be made to keep their families together, to enable them to live in their own communities and to support family and community groups who are working with this objective. In planning rehabilitation and supportive programmes, it is essential to take into account the customs and structures of the family and community and to promote their abilities to respond to the needs of the disabled individual. (p. 5)

For some recipients of extensive rehabilitation, outcome goals and treatment objectives are developed in a strange urban setting, away from their own home environment. Numerous authors have already criticized the present health care system for being insensitive to the diverse cross-cultural needs of its consumers (French, 1992; Groce & Zola, 1993; Kleinman, Eisenberg & Good, 1978; Lowrey, 1987). Winnipeg's two tertiary health care centres do offer interpreter and social support services through their Native Services Departments, but these services are limited and cannot replace the contribution of family members. The current structure of rehabilitation services for Aboriginal peoples in Canada does not meet the international standards set by the United Nations. The recommendations by the United Nation's *World Programme of Action Concerning Disabled Persons* (1983) state :

Rehabilitation should take place in the natural environment, supported by community-based services and specialized institutions. Special institutions, where they are necessary, should be organized so as to ensure an early and lasting integration of disabled persons into society.

To achieve the goals of "full participation and equality", rehabilitation measures aimed at the disabled individual are not sufficient. Experience shows that it is largely the environment which determines the effect of an impairment or a disability on a person's daily life. (p. 6)

The providers and planners of rehabilitation programmes need to consider the above while either initiating or maintaining service interventions. An examination of current service provision will underline the necessity for on-going evaluation of resource allocation.

5.1 PHYSIOTHERAPY

Physiotherapy assists people to optimize the motor skills necessary for independent functioning and mobility. The terms *physiotherapy* and *physical therapy* are synonymous, but *physiotherapy* is used more commonly in the province of Manitoba. There were 452 practising physiotherapists in Manitoba in 1996 (Loveridge, Pereira, McKechnie, & Pruden, 1996, p. 2). This includes those employed part-time and full-time, in private practice and in publicly funded positions. The total number of equivalent full time physiotherapist positions which were publicly funded in 1996 was 228.2 (p. 6). One equivalent full time position (1.0 EFT) is based on a 37.5 hour work week, or 1950 hours in a given year. The current average ratio of publicly funded physiotherapy positions in the province of Manitoba is one EFT to 5,025 people (p. 8). Similar data for Canada as a whole is not available due to different provincial methods of gathering statistics.

A "gold standard" for the ideal physiotherapist to population ratio does not exist. Satisfactory levels of service provision will depend upon the health status and demographics of a given population, as well as upon the type of impairment or ensuing disability. For example, an individual complaining of an uncomplicated tennis elbow will take less direct therapist time than an individual with diabetes, diabetic retinopathy and peripheral vascular disease, presenting with one-sided weakness following a stroke. If this same individual does not speak English, much of the allotted therapy time may be spent on interpretation. In recognition of this wide range of variables, neither the national *Canadian Physiotherapy Association*, nor the provincial governing body, the *Association of Physiotherapists of Manitoba*, currently specify a fixed treatment allocation for a specific impairment.

Outreach physiotherapy services to isolated First Nations communities were first initiated in the 1970s by the physicians at the Children's Hospital in Winnipeg. This was in response to a perceived need for community follow-up of First Nations children frequently admitted with respiratory ailments, such as bronchiectasis and bronchiolitis. As Medical Services Branch expanded the speciality services travelling into remote communities, the Arthritis Society was approached to complete feasibility surveys for four such isolated communities. These initial surveys were performed in 1980. Over the next seven years, services were expanded to include all ten fly-in First Nations communities in the South Zone of Medical Services' Manitoba Region. The North Zone of Manitoba has undertaken rehabilitation needs assessments, but due to fiscal restraints, was unable to implement the recommendations. The only health centre in the North Zone to have physiotherapy services on-reserve is the Norway House Hospital. Residents of other northern reserves must travel to the nearest provincial health centre, such as in The Pas, Thompson, Flin Flon or Churchill to access physiotherapy services.

Practitioner Distribution

The most recent available data refers to the former health regions, before the Manitoba Regional Health Authorities came into place in April, 1996. The health regions of Manitoba as they formerly existed are depicted in Figure 10. The physiotherapist to population ratios for 1996 in these various regions excluding private practice, are shown in Figure 11. In Winnipeg, the average ratio is one physiotherapist to every 2,728 people (Loveridge, Pereira, McKechnie, & Pruden, 1996, p. 13). When comparing these ratios to those of rural areas of Manitoba, significant disparities become apparent. It would seem

that some regions in particular are vastly underserved. In the northern region of Thompson for example, the regional average is one EFT physiotherapist to every 16,899 people (p. 21). In the Eastman region, the regional average is 1:21,374 (p. 25). The lowest served region is the Interlake, not shown in Figure 11, where the average therapist to population ratio is 1:552,029 (p. 26), where there is only a 0.1 EFT publicly funded physiotherapist.

Figure 10
Manitoba Health Regions, 1995

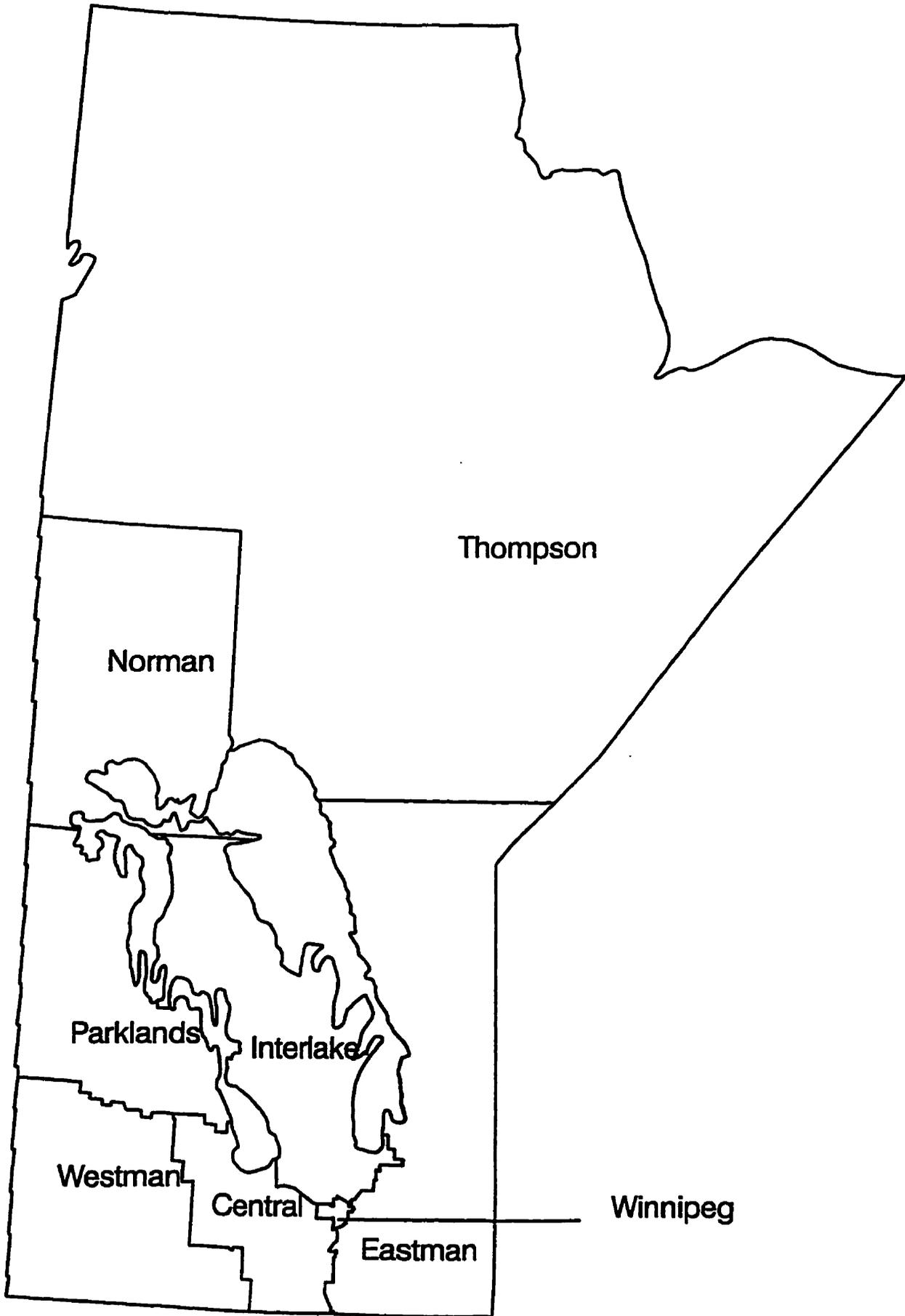
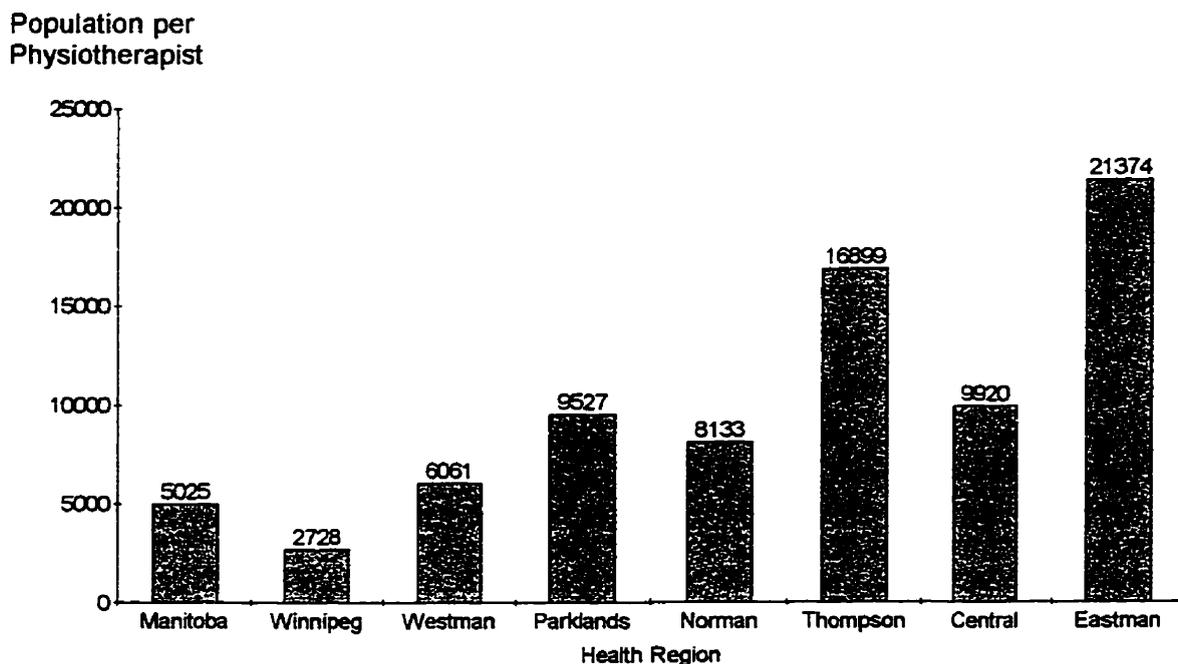


Figure 11
Population Per Publicly Funded Physiotherapist, Manitoba, 1996

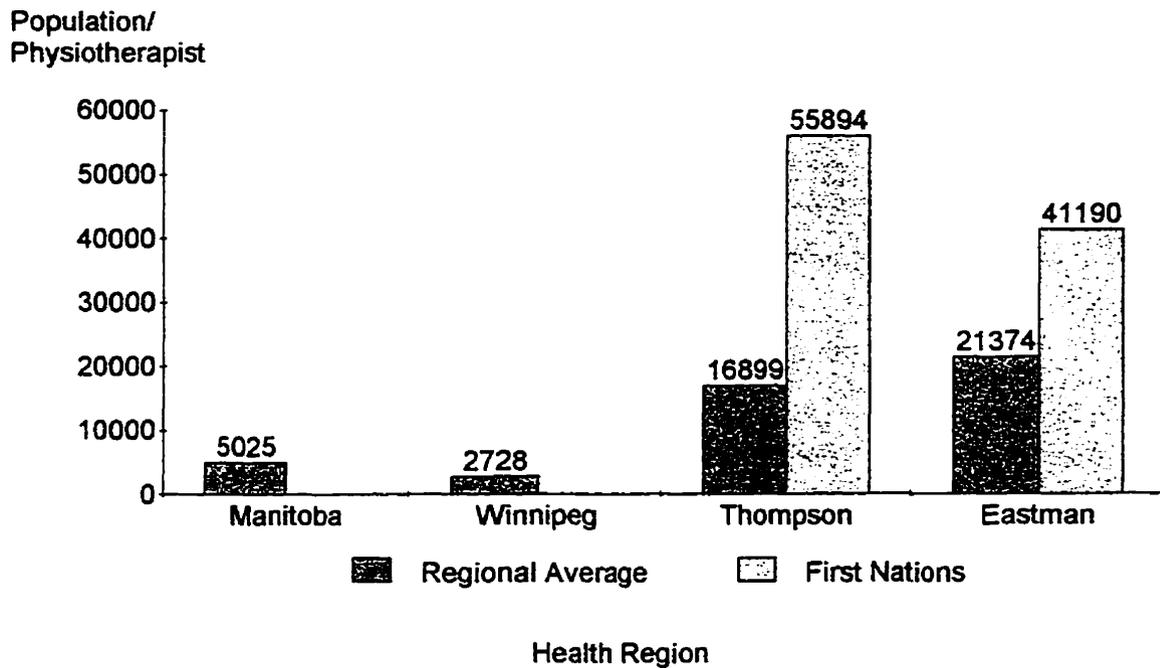


(Loveridge, Pereira, McKechnie, & Pruden, 1996, p. 11)

This provincial data does not, however, show the even greater disparities for publicly funded physiotherapist positions dedicated to First Nations specifically. Figure 12 depicts the population to publicly funded physiotherapist positions in two of the three health regions where dedicated First Nations services exist in the province of Manitoba. The other seven health regions have no dedicated First Nations therapy programmes. Manitoba and Winnipeg data are presented for comparison. The eighteen non-road accessible First Nations communities in the province fall under the two former health regions of Thompson and Eastman, the new Burntwood and North Eastman Regional Health Authorities respectively. The federally funded Norway House Hospital in the Thompson region, although road-accessible, is serviced in a similar fashion

to the non-road accessible communities due to the long travel time required by the visiting physiotherapist.

Figure 12
Population Per Publicly Funded Physiotherapist
Dedicated to First Nations, Manitoba *, 1996



* Adult Services only

In the Thompson region, the average ratio of service delivery dedicated to the First Nations communities is one physiotherapist to 55,894 people. This represents a three fold difference when compared to the regional average. In the Eastman region, the average ratio is one physiotherapist to 41,190 people, almost a two fold difference from the regional average. While First Nations can access off-reserve services available to all Manitobans, timely, readily accessible and culturally appropriate service delivery cannot be guaranteed. Extensive treatments may only come at the cost of relocating to an urban centre, a sacrifice that many individuals may be unwilling to or unable to make.

Service Provision to First Nations

Medical Services Branch (MSB) currently supports access to a physiotherapist on 10 of 62 First Nations communities in Manitoba. These communities are inaccessible by all-weather road and/or rail. They are generally serviced by small aircraft, or by winter road for approximately two months a year. Eight other such First Nations communities in northern Manitoba, representing more than 9,000 people, receive no physiotherapy services on-site. The 44 First Nations communities which are road accessible receive no physiotherapy services directly on location. People requiring physiotherapy are expected to access services at the nearest provincial health centre off-reserve. An anomaly in the current model is the federal Percy-Moore Hospital, located off-reserve in Hodgson. It serves the neighbouring First Nations communities of Peguis and Fisher River, as well as the local non-Aboriginal population. Physiotherapy services in this federal hospital are also supported by Medical Services Branch of Health Canada.

Physiotherapy services are provided to the isolated First Nations communities by the *First Nations Therapy Programme*, managed by *Community Therapy Services Inc.* The length of visits varies depending upon the size of the community. A list of First Nations communities and frequency of service is presented in Table 1. The frequency of service is comparable to their provincial off-reserve counterparts for communities of similar size.

All physiotherapy services must be provided at the local health centre or nursing station. Home and school visits, crucial components in assessing an individual's ability to function within his or her own environment, are not funded under the First Nations Therapy Programme of Community Therapy Services on-reserve. Home visits normally fall under the auspices of the provincial

Table 2
Physiotherapy Services
Provided by First Nations Therapy Programme
to Isolated First Nations Communities

<u>Hospital / Health Unit</u>	<u>Frequency of Service</u>
Norway House	5 days per month
Garden Hill	2 days per month
Red Sucker Lake	2 days per month
St. Therese Point	3 days per month
Wassagamach	1 day per month
Berens River	2 days every 6 weeks
Little Grand Rapids	2 days every 6 weeks
Pauingassi	2 days every 6 weeks
Poplar River	2 days every 2 months
Bloodvein	2 days every 2 months

Continuing Care programme, which does not view reserves as part of its mandate.

Despite Medical Service Branch's support of physiotherapy services to remote communities for the last few years, certain trends over the last two years are apparent. Until April 1, 1995, Medical Services Branch (MSB) paid for the transportation, accommodation (food and lodging), and direct service time of a physiotherapist on-site to 10 of the 18 remote northern communities. Accommodation is generally comprised of a bed at the local nursing station and food from the local Northern Store. As of April 1, 1995, Medical Services Branch withdrew its funding for the clinical services of the physiotherapist. Physiotherapy is a provincially insured service, and therefore billing for direct service time was transferred to the Manitoba Health Services Commission. The Medical Services Branch continues nonetheless, to support the community visits through transportation and accommodation subsidies. In August, 1996, the food subsidy came under review without any prior warning. While discontinued for resident nurses, it remains under negotiation for the transient health care

workers, including the physiotherapist, the doctor, the dentist, and other health care specialists. On the eve of health transfer agreements between the federal government and First Nations, criticism is mounting that these cost-saving measures reflect shrinking transferable funds.

First Nation Consumer Perspectives

Pursuing a critical consumer analysis is difficult at best where individuals are unfamiliar with a particular service. The benefits and rationale of rehabilitation, for example, may be quite foreign to persons whose exposure is limited to intermittent consultations only. Where services are scarce, any access to services at all may be construed as beneficial. For persons who have never received rehabilitation services before or since, meaningful evaluations may be limited. Comparisons with other health care providers or management alternatives may be impossible. Perceptions of service delivery, however, can still be pursued in terms of the impact on the individual.

Key First Nation informants working within the health care system in Winnipeg expound the lack of familiarity of First Nations with physiotherapy.

I guess that's a problem that a lot of native patients have. They aren't used to physiotherapy. There was none up until ten years ago. So, it's a new thing for them. And Rehab services are pretty well nil.

They don't know why physio is there for them. You know, it's hard to explain to them why physiotherapy is doing that to them. I remember patients coming home from the hospital and they would come into the nursing station and say, well, I had this nurse, because everybody that sees them is a nurse, that was pulling on my arm. And pulling it this way and then ever since then, it's been really sore. And then you find out later it was physiotherapy doing these exercises.

Physiotherapy interventions may seem strange if the rationale for the activity is not fully understood. In a culture where the link between behaviour and wellness is only recently gaining recognition, individuals may not appreciate the importance of activity and its effect upon the body's functions.

They (the community) don't think if you exercise and you exercise your muscles, they get strong and get the circulation going. They don't think that way. You know, because a long time ago, they used to work hard and they didn't have any problems like that.

When they have joint pain or they need to exercise a certain joint, they tend to immobilize it and they think that is going to take the pain away. They don't understand why, after the pain has gone, they don't understand why their arms or legs may not be functioning as well as they should. They didn't have medical terminology for a lot of physio, I mean, body parts, like muscles and stuff like that. We're starting to translate medical terminology so people can understand.

Within these confines of a recognizably limited context, an attempt at exploring consumer perspectives of physiotherapy was carried out.

Impact of Physiotherapy

In pursuing the positive impact that physiotherapy services may have had during the course of rehabilitation, recent recipients of physiotherapy services were asked to identify what their favourite activity was during their therapy sessions. Responses included: "to start walking"; "exercise, moving"; "I liked all the things".

In contrast, when asked which activities they found to be least beneficial, they were unable to identify any such non-beneficial aspects of therapy intervention.

Interpreter: He liked everything that they did.

Nothing (was a waste of time).

He didn't not like anything. He loved everything. He was just happy to be helped.

None of the respondents had any words of criticism about the services that they had received. Nor did any of the three recent recipients of service have any suggestions on how to possibly improve the physiotherapy services that they received. It is difficult to imagine that during the course of a combined estimate of over 150 physiotherapy hours, there was no indication for a modification in treatment approach. An apparent inability to explore the parameters of treatment provided may be explained by an unfamiliarity with different management strategies and options. Yet an apparent unwillingness to seem dissatisfied with services may also be partially explained by cultural norms.

Another First Nations person living on a remote reserve in northern Manitoba was reluctant to criticise the fact that the ramp into her home was left uncleared. The two feet of snow and old debris covering her ramp precluded a quick and safe exit from her home in case of emergency. When asked if she had requested that the band council attend to the matter, she replied as follows:

I don't like to complain. I'm thankful for all the Band does for me.

Anecdotal evidence, presented at a public meeting on Social Policy Concerning Manitobans with Disabilities (Winnipeg, March 4, 1997), suggested that First Nations people are culturally unaccustomed to complaining. The interpreter working with this project felt that "as long as they're getting better, they're happy." In her investigation surrounding the events leading to the 1991

inquest of a young Manitoba Ojibway boy's suicide, Ruth Teichroeb (1997) elaborates on the concept of "non-interference" or "preserving harmony" among First Nations:

Aboriginal social norms have long been aimed at preserving harmony between people, as the commissioners of the Aboriginal Justice Inquiry explained in their report. In the past, group cohesiveness was crucial for survival. Today, the ethic of non-interference means respect for others' privacy and a great reluctance to intervene in another's personal affairs. The popular mainstream tactic of confronting conflict head-on is an anathema to many Aboriginal people. (p. 99)

The apparent satisfaction with all aspects of physiotherapy services may also be in keeping with the historically paternalistic relationship between Aboriginal peoples and the dominant medical institutions. Perhaps certain individuals feel that if they complain, services will be discontinued.

In keeping with current trends in health care for "quality of care" and "client-centred care", physiotherapy departments in Manitoba are increasingly utilizing client satisfaction questionnaires. Given the above responses during open interviews, the validity of these self-administered satisfaction questionnaires comes into question. Alternatively, it could be argued that anonymous responses in a written questionnaire may prove more valid, providing that the population is functionally literate. Further elaboration of this issue is beyond the scope of this study.

Physiotherapy Outcome Goals

Physiotherapy intervention strategies are dictated by the underlying goals of rehabilitation. Successful rehabilitation outcomes are only possible when

those involved agree upon the goals of the interventions and what is mutually defined as 'success'. As a result of a growing consumer philosophy in the realm of health care, patients are more frequently referred to as 'clients', and treatment contracts between provider and recipient are not unfamiliar. In this context, First Nation consumers of physiotherapy services were asked if they or their families had been consulted in the process of setting goals for their rehabilitation. None of the individuals answered in the affirmative, regardless of the type of impairment.

Interviewer: Did they ever ask him at the hospital, what his expectations were, what his goals were? Did they ask him what he wanted to do?

Interpreter: They didn't ask him any questions about what his goals were; what he was doing; what they were trying to do for him.

This individual was not only excluded from setting the goals of physiotherapy, but was also apparently not given the rationale for the interventions provided. The following respondent indicates that he had no specific goals for treatment, yet his vocational needs were left unaddressed:

Interviewer: Was he ever asked what his goals were, what he wanted out of Rehab?

Interpreter: He was never asked.

Interviewer: Did he get a chance to speak to them, to the therapist, through a translator?

Interpreter: Yeah.

Interviewer: Does he wish that he could have told them what his goals were? Would he have liked the opportunity to tell them what he would like to do?

Interpreter: He said he didn't really have any goals.

Interviewer: What about returning to work? Was he hoping that he would return to work?

Interpreter: He didn't ask anything about working.

Interviewer: How come he didn't ask them about work?

Interpreter: He said that the interpreter from Medical Services didn't really actually come that often, only sometimes.

Interviewer: Would he have liked to talk to somebody about work?

Interpreter: Yeah, that's what he said.

Perhaps this individual was not aware of the wider parameters within which rehabilitation services function. If he was never informed of this however, it is unlikely that he would ever have initiated such a discussion.

Recommendations for Physiotherapists

While none of the previous recipients of physiotherapy had any suggestions for improving service delivery to people from First Nations, a First Nation key informant, who formerly worked as a health care provider with First Nations, did have some valuable advice. She emphasized that the preferred method of learning is with visual aids. The selection of the media used for education purposes must be accessible to all, regardless of education level achieved.

They're a visual people. They learn better by seeing things. I guess I can suggest for physiotherapy, not just for physiotherapy but for other people in the medical profession, if you want to educate people and make them understand this is what is happening to their body, get them a chart that has all these

different body parts or a visual model and explain to them this is how your joints move, or your muscles move, and this is why you need to exercise them. Maybe give a demonstration as to what happens when you lose muscle.

I guess that's one suggestion I can make - use more visual aids when you are explaining things to people.

She also advises physiotherapists to look beyond the confines of the rehabilitation setting. She emphasizes the role of the family in successful rehabilitation outcomes, and the lack of continuity that exists from the institution to the community.

If you are working with individual people that are coming down from up north and you're doing all this physiotherapy, then you're going to have to look beyond the hospital area, as to what type of services are available up in the home communities. It's important to continue with the therapy services and to involve the family with the therapy. Because you and I know that the families are not allowed to come down with the patients, so they don't get to see what's being done.

She recognizes a lack of provider knowledge and understanding of the community context within which this individual needs to function. This often results in a lack of transferability of the skills and strategies learned in rehabilitation to the community setting.

That's an important thing too for any physiotherapist who wants to work with people up north. They have to learn the communities, they have to learn the culture. Know the barriers that are up there for them, and also to be innovative.

When you go through Rehab services, they give you all this information on how to make your life easier, once you are out in the community, not realizing that you don't have that stuff. So what's

the purpose of giving out this information when they know we can't have it?

Without an understanding of the context within which an individual needs to function, rehabilitation efforts are at risk of failure. While therapists may feel that they normally do consider the home environment during the course of therapeutic interventions, the unique situation of First Nations in terms of housing, geography, socioeconomics, and access to services cannot be discounted. The responsibility falls upon the rehabilitation team to explore the various needs of all individuals, be they personal care, mobility needs or vocational. The rehabilitation team must view itself in a facilitating role in terms of assisting the individual to meet his or her own needs, both physical and spiritual.

Physiotherapy Provider Perspectives

There are very few if any physiotherapists in the province of Manitoba, who work exclusively with First Nations people. However, physiotherapists working in certain regions or specific hospital programmes will likely have greater contact with individuals from First Nations. These physiotherapists, in particular, may recognize the complexities involved in coordinating services and medical equipment for individuals from First Nations. From programme resources to benefit entitlement to travel arrangements, the intricacies of Aboriginal health care are complex. In large urban institutions, the burden of many of these tasks has been delegated to various disciplines; while reducing the demands on the individual practitioner, this practice of delegation also risks discontinuity in care. A solution commonly proposed to overcome many of the barriers arising in coordinating Aboriginal health care services is improved

communication. An overall theme of communication barriers can be seen throughout the physiotherapist narratives that follow. Limitations in communication will affect therapeutic relationships, as well as contribute to barriers in service provision.

Communication

Poor communication between health care planners, funders and providers has often been cited as one of the barriers in Canada's Aboriginal health care delivery. People voice their frustration while working both within the system and around the system. Some of this frustration may stem from the imposition of one culture's set of rules and expectations upon another. In terms of health care, this can affect how therapeutic interventions are perceived, as well as how professional relationships are nurtured. A physiotherapist provides an example of misinterpreted communication with a patient in her workplace:

I think people get frustrated because they don't take the time to try to understand. A perfect example, and nothing to do with physio; we were trying to get one of the clients on self-meds. The nurses were getting frustrated because they would put 'at 8 o'clock in the morning, you take this medication, at 8 o'clock at night you take this medication'. Well, 8 o'clock doesn't mean anything if you're from a northern community and the sun rises and the sun sets, whatever.

So somebody on the team came up with a solution. And it was so simple, that it was ridiculous when we thought of it. But we drew pictures. We drew a picture of the sun rising and we drew a picture of a sun setting and gave it to the patient. We never had a problem after that. And it's not putting the patient down, we're trying to make people understand our culture without us trying to understand their culture. And it was a very simple thing to do.

By being flexible and somewhat innovative in their approach to communication, they were able to convey their message to the patient. Lucille McRae (1994), a rehabilitation nurse, writes that "rehabilitation staff working with Native Indian clients often experience feelings of frustration when their teaching is not understood in the context in which it is given and the client does not 'comply' " (p. 251). Health care workers must learn to employ all aspects of their communication skills before labelling anyone as 'non-compliant' with therapy.

I don't think it's less compliance. I think they just don't understand what we're trying to tell them. And I don't think we're taking the time to tell them.

On the whole, I find that the people that I deal with in these communities are very compliant with health care teaching that I try to give, once I've been around long enough to learn how to do it properly. Very sensibly, people in northern communities tend not to do it just because some expert tells them to do it. They have to understand the use and they have to see how it applies to them. I do find my practice style has changed over the years; that I spend a lot more time teaching and explaining, than doing active treatment. I tend to do a lot of assessments and explaining why I think they should do things, rather than as much 'hands-on' as I would do if I were working in the clinical setting in the south.

Inappropriate communication is a barrier for the individual trying to access the services. Health care workers must adjust their teaching methods to the culture of the recipient. If they are unsure of the best strategies to do this, it is their responsibility to collaborate with those who can assist them in choosing the appropriate approach. Without appropriate communication techniques, treatment outcomes will be limited to passive interventions. Communication does not only include shared language skills, but also an understanding of the cultural context within which individuals function.

Cultural Context

Therapists working in southern urban settings with clients from remote First Nations communities must recognize the context within which they are encouraging their clients to modify their behaviour. Therapists who have the opportunity to work in the communities locally are likely to recognize this much sooner. They need to consider the resources realistically available to the client in a given socioeconomic, political, and environmental climate. The limitations that individuals face in terms of prevention of disability and follow-through of exercise prescriptions must be considered in any therapeutic intervention. A physiotherapist working in northern Manitoba describes the limitations she has witnessed in terms of behaviour modification:

Half of the health care problems they've got where I work is related to people who are diabetic. Technology's not going to do much for that... lifestyle changes and getting to the whole socioeconomic issues. If it costs a third more just to eat there, are you going to have access to the health food choices? If you're bored and you have no road to walk on and nothing to do, are you going to be physically active enough to control your Type II Diabetes? Probably not.

You could say that people should exercise, but unless there's some ability to do it in a way that's socially acceptable and pleasant enough to motivate people to keep on doing it, will you do it? Probably not. How many people spend quite a lot of money in Winnipeg on spa memberships and go three times a year and that's it? Why should it be any different up north when you don't even have the spa?

Physiotherapists try to alter their treatment approach to one that is feasible and meaningful to every individual they encounter. Treatment approaches with First Nation clients may require further modifications of conventional strategies.

Jurisdictional Barriers

A physiotherapist working with First Nation clients must not merely be aware of geographical and cultural considerations. The political infrastructure dictates where and how often clients can be seen by the therapist, as well as the clients' accessibility to special devices or home modifications. As described earlier, frequent changes in the current health care system preclude any permanent assumptions about responsibility. A physiotherapist familiar with both the federal and the provincial systems of health care provision and benefits, expounds on the frustration she experiences while attempting to work within these two systems:

I think politically that's probably where my greatest frustration lies - it's this whole business of getting equipment, the delays in getting equipment, some of which is just the situation. If I were trying to get equipment for somebody in Thompson, I would still be faced with a lot of these same delays because they would be related to getting things shipped, trying it, and seeing if it works, sending it back, that kind of thing. And I don't see that there's any way around that. But the differences between what you can get in the Non-Insured Health Benefits system, and what you can get in the provincial system, whether or not people get Home Care, all of that kind of thing, can be very frustrating to work around at ground level. Philosophically, when you look at whether those differences should be there, that's a whole other issue. But when you're working on ground level and having to sort these things out, it's terribly time consuming. There has to be limits, I'm sure. And there has to be criteria. But some of these little semantic things seem to me to be an undue barrier to my getting things done.

The practitioner who makes the recommendations for patient equipment must first disentangle the web of appropriate forms and then hope for approval. Once again, improved communication between funders and prescribers could make the task less cumbersome, thereby saving time, frustration and ultimately costs.

Discontinuity in Care

The lack of support services and infrastructure at the community level has become apparent in hospital efforts at discharging patients home with appropriate supports in place. Overcoming the issues surrounding services on-reserve has delayed discharges from urban hospital settings. During a time of increasing pressure towards early-discharges from hospital, a lack of the necessary support services has put greater strain on the in-patient services.

If they are, say a bilateral above-the-knee amputee, and they're going home in a wheelchair, or if they're a spinal cord patient and they're going home in a wheelchair, a lot of the reserves don't have running water... a lot of the Bands are not very supportive, and their homes are wheelchair inaccessible and they're not willing to renovate them, and whatever. So yeah, it can be a big problem.

The problem, I guess, that we have, is getting consistent help once they get out there. A lot of the people who go home in a wheelchair are going to stay in a wheelchair and are going to require a lot of daily consistent Home Care. I can think of one lady who came from the Interlake area. She was the Home Care worker and presented after a motor vehicle accident. We had to "hospital hold" her because we were unable to get assistance into that community. So she moved to a closer hospital.

Rehabilitation teams may find persons from First Nations are physically ready to return home, but without the support services health care workers have

come to expect in urban areas, discharges from hospitals are delayed. Individuals may choose to return home despite a disruption in their continuity of care. The health care team is left with a feeling of uncertainty regarding the safety and feasibility of the discharge.

5.2 OCCUPATIONAL THERAPY

Occupational therapy helps people to maximize their function in areas of self care, productivity, and leisure within the chosen environment, both in the home and in the community. The occupational therapy profession advocates a holistic approach to practice, recognizing the interaction of mental, physical, socio-cultural and spiritual factors in an individual's overall state of health (*Canadian Association of Occupational Therapists* as cited in Scott, 1997, p. 90). There are currently 320 practising occupational therapists in the province of Manitoba (Sharon Eadie, Executive Director, *Manitoba Society of Occupational Therapists*, personal communication, 1997). This includes both part-time and full-time, those privately and publicly funded. It is estimated that roughly 95-98 % are funded through public monies. Many third party insurance plans do not include occupational therapy services in their coverage.

Most provincial personal care homes in Manitoba are provided with the services of an occupational therapist, funded by Manitoba Health. In collaboration with residents and caregivers, therapists provide consulting services including resident assessment, management recommendations and on-going review. The goal of the interventions is to optimize the individual's comfort, safety and level of independence. None of the seven federal personal care homes in Manitoba currently employ an occupational therapist on a regular basis. Federal personal care homes fall under the mandate of the Department of Indian Affairs (DIAND), who in turn utilize the expertise of Medical Services Branch where medical intervention is warranted. In terms of occupational therapy services in federal personal care homes, DIAND feels it is the responsibility of Medical Services. Conversely, Medical Services does not recognize the medical role of occupational therapy and feels it is the

responsibility of DIAND. The residents of the personal care homes who go without service are the ones who suffer the burden of this ongoing jurisdictional battle. Alternatively, Sagkeeng First Nation has chosen to act independently of these two government departments. The Sagkeeng First Nation Band Council has privately contracted the regular services of an occupational therapist and a physiotherapist for the federal personal care home in their community. Other band councils are also privately contracting consultation services of an occupational therapist on an irregular basis. While several communities have requested services similar to their provincial counterparts, both Medical Services and the Department of Indian Affairs have refused to fund such programmes (Shirley Ladd, Director of Rehabilitation Services, Community Therapy Services Inc, personal communication, November 5, 1997).

Occupational therapy has been deemed a matter of 'leisure' and 'lifestyle', not medical need, by the Medical Services Branch of Health Canada. It is therefore not routinely provided on reserve. It can be obtained however on an ad hoc basis in the road-accessible communities, but not in the 18 non-road accessible First Nations communities in Manitoba. The process of medical justification and the completion of various approval forms can take several months to complete, with no guarantee of approval.

If someone from a remote community does require the input of an occupational therapist, they need to be referred by a physician to an appropriate health centre, usually in an urban setting. The two tertiary hospitals in Winnipeg, where the majority of northern residents are referred, have very limited out-patient occupational therapy programming available. A hospital admission is often the only recourse to access the services of an occupational therapist. The extent of the occupational therapy intervention while in the acute

care setting, however, is often dictated by the length of stay and available resources. Current trends to reduce lengths of stay in the hospital make it increasingly necessary for occupational therapists to prioritize both clients and their problems. Issues deemed to be seemingly less important for an individual are inevitably left unaddressed while in the hospital. The cultural and community context of these various activities of daily living are at risk of being overlooked in busy hospital schedules. These issues are either left to the family practitioner or, where resources are available, referrals are made back to the community. For persons from First Nations living in remote communities, this is not an option. Either there is no rehabilitation therapist at all who visits the community in question or a physiotherapist is all that is available.

Community occupational therapy needs assessments were completed at the request of Medical Services Branch in several isolated communities in both the South and North Zones in the late 1980's (Shirley Ladd, personal communication, September 16, 1996). Recommendations were made at the time that an occupational therapist visit the communities roughly every three months. The services would focus primarily on physical medicine in communication with the physiotherapist. Mental health issues, another strong component of occupational therapy, were temporarily deferred. This decision was made on the basis of the cultural and language barriers that a non-Aboriginal practitioner would have to face (Margrét Thomas, personal communication, September 13, 1996). The mental health needs of the communities were felt to be addressed by programmes already in place, such as *Brighter Futures* and *National Aboriginal Drug and Alcohol Programme*. Margrét Thomas, a member of the survey committee at the time and current co-ordinator

of the *First Nations Therapy Programme*, describes the ensuing results of the recommendations:

Everybody agreed that, yes, occupational therapy is necessary. However, Medical Services Branch took the position that occupational therapy is not a non-insured benefit. It is a lifestyle, educational, life enhancing type of discipline and, therefore, would be properly seen as the responsibility of the Department of Indian Affairs. The Department of Indian Affairs took the stance that if you call it therapy, it's medical... So everybody accepts that it would be a very useful thing to be provided, but, and a big but here, it was seen by these two departments as the responsibility of the other department.

This is confirmed by Cathy McGuire, then South Zone Nursing Officer for Medical Services Branch (personal communication, September 20, 1996).

They think occupational therapy is beading or something along those lines. I think, quite possibly, we've got people at the policy-making level, who don't realize the here and now of some of these occupations. Or they might think that occupational therapy is a totally social sort of thing. They don't realize that occupational therapy is real. We consider occupational therapy a medical modality.

Although she and her office staff may recognize the role of an occupational therapist in the medical model, without approval from Ottawa, occupational therapy will remain non-accessible in many First Nations communities in Manitoba.

Occupational Therapy Consumer and Provider Perspectives

Specific exploration of occupational therapy consumer and provider perspectives were beyond the scope of the current study. Roxanne Scott (1997) found the following difficulties and concerns identified by occupational therapists practising in cross-cultural settings:

1. Difficulty in accurately interpreting the client's behaviour in cross-cultural clinical encounters. "When a therapist and client come from different cultural backgrounds, a client's behaviour is often not what the therapist is expecting. Confusion arises as to how to interpret the client's behaviour, and inaccurate observations result" (p. 92). Current behavioural and cognitive assessment tools are generally culture-specific and insensitive to cultural differences.
2. Subtle differences in language usage, often leading to poor communication and misunderstanding. Where the primary languages differed, interpreters were felt to be beneficial. However therapists found it difficult to ascertain the accuracy and completeness of the information relayed.
3. Reluctance to communicate with the therapist. "Some therapists questioned whether the inherent inequality in status and power in the therapist-client relationship could affect the ability for open communication between themselves and their clients who are from a different cultural background. They suggested that these particular clients might have feelings of being overpowered and coerced in a treatment situation. The result could be that they feel unable to provide input into their health care decision" (p. 92).
4. Feelings of frustration in the therapeutic relationship with clients. Reciprocal misunderstandings in conjunction with language difficulties resulted in ineffective communication. This permitted only superficial relationships to be formed.

The author promotes a truly client-centred approach to occupational therapy. She states that this approach requires that practitioners recognize the uniqueness of their clientele, and allows them to determine the goals of intervention. Understanding the client's experience of occupational dysfunction

must incorporate the individual's larger social and cultural environment (Scott, 1997, p. 94). This perspective is best obtained when the client is interviewed in his or her natural setting.

Gage, Cook and Fryday-Field (1997) question the primary needs of the client as identified by occupational therapists in the acute care setting. While self-care and home management are often recognized as the principal issues to be addressed before an individual is discharged back to community living, the authors argue that these values are based upon those of the practitioner, not necessarily the client. In this study, former recipients of occupational therapy in a southern Ontario community complained of a lack of attention by the therapist to their psychosocial needs while in the hospital, and frustration with the availability of community services upon return to the community (p. 99). The authors conclude, that an individual's perceived self-efficacy for essential post-discharge activities is more important than those of the health care provider in terms of successful discharge planning (p. 100).

5.3 SPEECH AND LANGUAGE THERAPY

Therapists working in communication disorders, or speech therapists, strive for the optimization of communication in speech as well as writing. There are currently 201 speech-language pathologists in Manitoba, part-and full-time, private and publicly funded (Kelly Lukaszewski, *Manitoba Speech and Hearing Association*, personal communication, 1997). The total EFT or equivalent full-time positions which are publicly funded are 140.7 in the province of Manitoba.

By the very nature of the profession, it is very difficult to dedicate therapists to specific language groups. It is not known by this writer whether any of the speech-language pathologists working in Manitoba have working knowledge of any Aboriginal language. The efficacy of using interpreters in this clinical setting has not been addressed by the current study.

At present, there are no speech-language pathology services dedicated specifically to the First Nations adult population in Manitoba. Access to publicly funded speech-language therapy is limited to those services generally available through hospital programmes. Lengthy waiting lists for these services are common.

5.4 VOCATIONAL REHABILITATION

Vocational Rehabilitation for persons with disabilities is a federal initiative in existence for over thirty years. In accordance with the *Vocational Rehabilitation of Disabled Persons Act*, it provides a fifty-fifty cost sharing mechanism between the federal and provincial governments. Run as part of the Department of Family Services in Manitoba, the primary focus of vocational rehabilitation is to provide people with disabilities the opportunity to pursue meaningful employment. Participants must be over sixteen years of age and Canadian citizens. Eligibility requirements include a documented disability: psychological, cognitive, visual, hearing, learning, addiction or physical impairments. Vocational Rehabilitation for Disabled People (VRDP) centres exist across the province including the regions of Winnipeg, Eastman, Westman, Central Manitoba, and Thompson. Although the programme was to expire at the end of 1996, funding has been extended for one more year. The budget for 1997-98 is set at \$168 million (Manitoba Coalition on Federal Provincial Disability Issues, 1997).

Consumer criticism about the programme emphasizes the lack of national standards across Canada (Manitoba Coalition on Federal Provincial Disability Issues, 1997). Despite federal cost-sharing, provinces are virtually in control of their own VRDP programmes. People with disabilities looking to improve their employment prospects find themselves vulnerable to the given political climate of the Ministries of Family Services and Finance. Lengthy waiting lists are also cited as limiting access to VRDP programmes.

While certain reserves have limited VRDP programmes, eligibility requirements for the programme dictate that a permanent residence must be established off-reserve before applications will be accepted. Although First

Nations persons are eligible to apply for this joint federal-provincial programme, individuals living on-reserve must first relocate, with or without their families, to new and unfamiliar surroundings. Data regarding the use of this programme by residents of reserves is not readily available for analysis.

CHAPTER SIX: HOME CARE SERVICES FOR FIRST NATIONS

The recognition that many people with severe physical and mental health impairments do not require permanent institutionalization is a relatively recent phenomenon. In fact, the first publicly funded home care programme in Canada was in Manitoba in the 1950s, in response to the poliomyelitis epidemics of 1952 and 1953 (Alcock, Hildes, Kaufert, Kaufert, & Bickford, 1984; Desmarais, Alcock & Hildes, 1956). Support services provided in the home enable an individual with a disability to remain in his or her own environment, at a lower cost than institutionalization (Manitoba Health, 1992). The wide range of available services play a crucial role in the active participation of persons with disabilities in the community.

Home Care is a provincially funded, non-profit programme administered through the Office of Continuing Care. The philosophy of this programme is that "individuals are more likely to achieve, and continue to maintain, a high level of well-being in the familiar environment of their own homes" (Manitoba Health, 1997a, p. 39). These services may include nursing care through the Victoria Order of Nurses; orderly care for personal hygiene; homemaker; respite care for family caregivers; Meals on Wheels; and rehabilitation in the home. The programme activities are meant to supplement, rather than replace, those efforts of the family and the community. Home Care services are delivered through the regional and sub-offices of Manitoba Health and through six designated rural District Health Centres. Four hospital coordinating Home Care offices also operate in Winnipeg. The total number of persons registered with the programme in 1996/97 was 29,783, representing a 15% increase from the previous year (Manitoba Health, 1997a, p. 40).

Self-Managed Care has been a programme option since 1991. In December, 1994, it was expanded to all Manitobans eligible for Home Care and who are willing and able to take on the responsibilities of managing their own non-professional personal care services that would normally be provided by Home Care. "We want to decide who provides our care, we want to take control" have been the comments reported by these self-managers (Andrews, 1996, p. 2). By making provincial funding directly available to adults with physical disabilities, self-managers are able to decide who provides the service, when, how and where they are provided. There are presently 83 "self-managers" participating, both in Winnipeg and rural Manitoba (Manitoba Health, 1997a, p. 39). The concept of self-management is not entirely new in Manitoba. Alcock, Hildes, Kaufert, Kaufert, and Bickford (1984) point out that in more than a third of the cases in the initial Home Care programme in the 1950s, the paid attendant was a relative of the patient.

Aboriginal persons with a disability living off-reserve may avail themselves of all provincial programmes. Yet these services have been criticized for not meeting the unique needs of Aboriginal persons. The report on *Aboriginal Persons with a Disability - Training and Employment Challenges* prepared by the Social Planning Council of Winnipeg [SPCW] (1996) explains the situation within which Aboriginal persons may find themselves:

Aboriginal persons with a disability (have) to make trade-offs. In order to get culturally appropriate programming and services, they may have to deal with a lack of knowledge among agency staff about disability issues. In order to have services that respond to disability issues, they may have to forgo the benefits of culturally appropriate services. Therefore, in many cases, only a portion of the challenges faced by Aboriginal persons with a disability is addressed. (p. 45)

The provincial Home Care programme is not available on-reserve in Manitoba. Formal training of Home Care workers in First Nations communities is rare. Trained orderlies and respite workers are not available, nor are any "self-managed" options. It is the view of the Medical Services Branch of Health Canada, that the provinces are responsible for the provision of any Home Care services to all its citizens. A key informant from the Manitoba Regional office of Medical Services explains their position:

All the provinces except two (Manitoba and Québec), provide, treat First Nations equally with other citizens. If I was a First Nation person living on-reserve in Saskatchewan, if I needed home nursing care, or any Home Care, it's provided by the provincial government. The same as anybody else!

The province is funded to provide Home Care services to everyone in the province by Ottawa, as far as Ottawa is concerned. The province of Manitoba says, oh, that's not enough money. Well, when the Capital Assistance Plan and the Equal Program Funding was started up, at the time when Medicare came in, it was a 50-50 cost sharing basis for medical and social programs. There were no strings put on by Ottawa to force the provinces into providing services to everyone in the province.

According to this informant, Manitoba is only one of two provinces across Canada where publicly financed Home Care services are not provided on-reserve. Nor does there exist a mechanism by which individual provinces can be forced to provide services equitably across its regions. Federal influence on a provincial programme is arguably dwindling even further as Ottawa slowly reduces its share of health care funding in its efforts to manage federal budgets.

If a First Nations person with a disability living on-reserve in Manitoba requires support services in the home, services are generally limited to homemaking. Homemaking services may consist of light housekeeping, meal

preparation, and laundry. Heavy chores such as chopping wood or hauling water, necessary tasks of everyday living for many First Nations families, are generally not included. To be eligible for homemaking services, a letter of request is required by the band council from the physician, nurse, occupational therapist or physiotherapist. The request will then be filled according to prioritization and available funds. For non-emergency situations, it can take several months to finalize. Although confidentiality regarding personal care is at risk in any small community, local care providers can offer an element of culturally sensitive assistance likely unavailable in large urban settings. Family members are often employed to provide these services. This may be an advantage to many families where unemployment rates are high and disability pensions are scarce. This option of paid family caregivers is not available in the provincially managed Home Care programme.

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), eight reserve communities are compared to eight non-Aboriginal communities in the Manitoba region. The provincial Home Care programme in Manitoba reportedly serves a clientele of which 77% are over the age of 65 (p. 42). In First Nations communities, the equivalent age group only represents 49% of the clients. Overall per capita hours of service per week provided for all Home Care services average 0.14 hours per week for First Nations communities, compared to 0.19 hours per week for the non-Aboriginal communities in Manitoba (p. 44). The hourly cost of homemaking services in First Nation communities is \$5 - \$5.50, compared to \$8 - \$10 per hour in their sample of non-Aboriginal communities. In 1992/3, the per capita provincial expenditure for off-reserve residents was \$397.98. This compares to an on-

reserve federal per capita expenditure of \$191.58. The expenditure on-reserve for continuing care services is only 48% of that for the off-reserve population. The authors conclude that First Nation clients are receiving only 62% of their homemaker requirements; 72% of their personal care requirements; and 22% of their home nursing requirements (p. 45). Existing services on-reserve are criticized for an overall lack of integrated programming, 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.

These disparities are confirmed when comparing the data from the household portion of the 1991 *Health and Activity Limitation Survey* (Statistics Canada, 1994c) with the 1991 *Aboriginal Peoples Survey* (Statistics Canada, 1994b). Table 3 presents the percentage of people with disabilities reporting on their needs for personal care, light house keeping and meal preparation. These three activities are normally included in the services provided by the provincial Home Care programme. Of particular note, is that First Nations persons living on-reserve in Manitoba, consistently report less need of help with personal care, light housekeeping, and meal preparation. Whether they do indeed *require* less help, or simply *report* requiring less help, is a finding that demands further investigation. Also of note is the higher reliance on family members for assistance on-reserve than for Manitobans as a whole. The survey did not explore the impact, if any, that these dependency relationships had upon either the individual or on the family members. Ninety-three per cent of the 590 persons, who reported that they required assistance in moving about within their residence in 1991, received the help primarily from family members (Statistics Canada, 1994b).

Table 3
Self-Reported Reliance in Everyday Activities

	<u>Personal Care</u>		<u>Light House Keeping</u>		<u>Meal Preparation</u>	
	<u>Manitoba</u> ¹	<u>First Nations</u> ²	<u>Manitoba</u>	<u>First Nations</u>	<u>Manitoba</u>	<u>First Nations</u>
Need help	8% ³	6% ⁴	21% ⁵	18% ⁶	12% ⁷	8% ⁸
Get help	53%	91%	49%	91%	56%	92%
From:						
- Family	43%	90%	62%	87%	73%	87%
- External Source (excluding friends/neighbours)	56%	29%	33%	26%	34%	28%

¹ data for the Manitoba population residing in households.
² data for the First Nations population living on-reserve in Manitoba.
³ see Appendix VI for specific *Health and Activity Limitation Survey* questions, C26, 27 and 29.
⁴ see Appendix VII for specific *Aboriginal Peoples Survey* question, C32.
⁵ see Appendix VI for specific *Health and Activity Limitation Survey* questions, C11, 12, 13 and 15.
⁶ see Appendix VII for specific *Aboriginal Peoples Survey* question, C29.
⁷ see Appendix VI for specific *Health and Activity Limitation Survey* questions, C1, 2, 3 and 5.
⁸ see Appendix VII for specific *Aboriginal Peoples Survey* question, C27.

(Statistics Canada, 1994b,c)

Cultural practices of choosing to care for one's own family members must also be considered. A key informant working as a Health Councillor for a Manitoba Band Council describes the role of the family in his community:

Right now, in our community, people are trying to help themselves and their families. That's what's happening right now, eh? Like washing and things, and helping them with their wash. I think we try to help each other out like that. But other people, like after operations, the workers help a little. We can do that for two weeks only. But people with disabilities, to do that, I don't know, it's... I don't think we can do that... they have families to look after them.

Key informants in this study, while willing to assist family members, also voiced their own limitations in providing the full extent of the support required. The same key informant Health Councillor reflected upon his own personal experiences:

I know that when my dad couldn't help himself, family members helped him through the worst of the problems... My mother didn't stay here, she couldn't do anything. There was nobody to help her, so she was alone. Nobody to take water, nobody to do that. She was an elder. I had a lot of problems doing things for her. I live on the other side (of the community) and she lived on the other side. We needed someone to look in on her sometimes.

The spouse and principal care provider of one study participant denied having anyone ever instruct her in how to assist her husband in personal care, an activity normally provided by Home Care attendants. This is in spite of the fact that her husband was in the hospital in Winnipeg for three months following a severe stroke, leaving one side of his body essentially paralyzed. Not having any running water, she found heating the water on the stove particularly cumbersome in caring for her husband. When asked if they would accept outside help if it were available, they answered affirmatively.

Another informant also responded that he and his wife would accept help were it available:

Interviewer: If he were in the city, does he think he would accept outside help to help him inside his house?

Interpreter: Yeah.

Interviewer: Is he getting any help here? And homemaker services?

Interpreter: No help here, no homemaker.

Interviewer: So, does his wife do all the cooking and the cleaning?

Interpreter: Yeah. She's doing things inside the house. He would like to have somebody to help her around the house.

In addition to the tasks of everyday home management, family members are forced to take on the responsibility of the personal care of the individual, activities normally assumed by orderlies in an urban setting. This role of caregiver falls traditionally upon the women of the family, who are then often obliged to forgo activities outside the home, including paid employment:

Interpreter: She (the caregiver) used to work before at the school and I guess she was told to look after her husband.

Interviewer: Not work and look after her husband?

Interpreter: Yeah.

Interviewer: Does she miss her work?

Interpreter: I guess people told her that she could have went on UIC (Unemployment Insurance Benefits). But other people say that she couldn't. She's saying that she's going to take a year off from work, to see how he's doing in a year. She says that there's nothing wrong with him. He can get himself a cup of tea.

Interviewer: Does she feel like he's safe enough to leave at home by himself during the day? She thinks she could go back to work?

Interpreter: Uh huh. She was willing to go back to work when they moved back (from Winnipeg).

Interviewer: So what's the problem here? Why can't she go back to work then?

Interpreter: Somebody took her job for a while.

Interviewer: Will she get it back when she wants it?

Interpreter: They want her to wait til September.

Interviewer: Who decided that? The Education Authority (her employer) or the Health Council?

Interpreter: The Education Authority.

Interviewer: They told her to stay home and look after her husband?

Interpreter: Yup. Her daughter is here to look after him anyway.

In this case, the female care provider was also the only household member who held paid employment. Although other family members were available to provide support, the responsibility of caregiver fell upon the shoulders of the spouse. Whether or not these tasks were assumed willingly, and whether the best interests of the entire family were considered, is not known. Interestingly, this coincides with a general political trend to shifting greater responsibility onto the family for providing long-term care needs. However, the response of families, particularly women, may not be so yielding in a different cultural setting.

Caregiving roles may assume different dimensions in different cultures. Whyte and Ingstad (1995) stress the need to consider the multicultural context of dependency relationships. "Reliance upon another person may be encompassed by love and a feeling of mutuality... In some cultures, sociality (family and community membership) may outweigh individual ability as a value" (pp. 11-12). The authors cite the work of Ann Goerdts in Barbados, where she explored the balance between autonomy and connectedness. "The unity of the group depends not only on the contribution of each member, but also on each member's willingness to accept help from others" (Goerdts as cited in Whyte & Ingstad, 1995, p. 12). While an in-depth exploration of the applicability of this

theory is beyond the scope of the current study, the cultural context of First Nations family members assisting those with disabilities cannot be overlooked. It is likely true that assistance is provided willingly. But where there are no options, care must be provided by families out of necessity. Unfortunately where economics may dictate migration to urban areas, the availability of large extended families to share the responsibilities may be dwindling. Traditional models of caring for those who need assistance may not always compliment modern family life necessities.

Home Care Equipment and Supplies

This aspect of Home Care was originally established as an equipment service in response to the polio epidemic in the 1950s. These services currently include the acquisition, storage, distribution, maintenance and repair of various supplies and equipment (Manitoba Health, 1997a, p. 40). Equipment is bulk purchased and provided on indefinite loan to Manitoba residents upon the recommendation of a health care professional. Equipment includes such items as bathroom aids, bedroom furnishings, support, and mobility aids. In 1996/97, 28,952 equipment services were provided through Home Care (p. 41). The number of registered clients increased from 21,785 in 1995/96, to 23,310 in 1996/97 (p. 41).

During 1996/97, the primary functions of purchase, distribution and maintenance of supplies and equipment was transferred from Home Care to the Materials Distribution Agency of Manitoba Government Services. Equipment and supplies are now loaned out, regardless of address, and billed to the Regional Health Authority (RHA). The effect this change has had on First Nations is apparent when considering the example of hospital beds. These beds

are particularly useful when assisting individuals who are too weak to move themselves independently in bed, such as those who are terminally ill. Previously, the loan of hospital beds for use at home was offered through the Home Care equipment pool. Historically, Home Care would not provide these beds on reserves due to jurisdictional boundaries. Until 1995, Medical Services Branch purchased hospital beds for individuals living in First Nations communities. Medical Services no longer provides this service, however, considering it never to have been part of its original mandate (MSB Authorization Unit, personal communication, 1996). In the interim, families who required such a hospital bed had no other recourse than to purchase the bed themselves for \$2-3,000 or to request the financial assistance of the band council.

With the implementation of regionalization of health services in April, 1997, and the new role of the Materials Distribution Agency of Manitoba, the procedures for the procurement of equipment have changed. Forms no longer require the distinction of residence on or off-reserve. Several requests for hospital beds in First Nations communities have since been filled. Whether this service will be continued once the Regional Health Authorities become aware that they are supporting services on-reserve in their regions is unclear.

CHAPTER SEVEN: ENVIRONMENTAL FACTORS

Equal access to one's physical surroundings is a right that many people take for granted. It is a right that citizens do not share universally. The physical environment includes both the manufactured aspect, such as buildings or transportation, and the natural outdoor environment. Either dimension may impede an individual's ability to move freely from place to place. Accessibility to one's surrounding community may also refer to the extent to which individuals can gain access to personal and public information systems or communication technology.

Universal accessibility may often be limited by the attitudes of people who feel that special considerations for individuals of differing abilities is not necessary. Persons with disabilities have claimed that in the past they have been systematically overlooked in terms of decision-making affecting their lives (Driedger, 1989; United Nations, 1983). Public transportation, public buildings, and public communication systems were developed without consideration of the needs of all the people they serve. Where accessible public services do exist, such as Handi-Transit in Winnipeg, the risk of budget cutbacks and privatization is ongoing (Chow, 1996).

To date, publicly funded services to improve accessibility have primarily benefited those people living in urban areas. Programmes have often been designed for an urban population without consideration for a rural setting or a different cultural context.

7.1 NATURAL ENVIRONMENT

The outdoor terrain will inevitably affect how easily persons are able to move from one place to another. Regardless of one's physical attributes, decisions around travel hinge upon land, water, and weather conditions. For those people with mobility impairments, the terrain may dictate when and where an individual may venture. Elderly persons, for instance, who experience an impairment with their balance may avoid walking on uneven ground or on icy pathways.

The unpaved roads, lack of sidewalks and the uneven terrain in many northern Aboriginal communities leave wheelchair users extremely vulnerable to climatic conditions, such as snow and mud. A health care provider working in Manitoba's north expressed her concern with wheelchair mobility:

The whole focus with wheelchairs, I think, originally was that they could be used as invalid chairs and transport chairs. They almost seem to be looking at giving people chairs that are primarily to be pushed around. But they're certainly not practical in the north for somebody who is in a community where there is no pavement, no snow clearing, except on the very major routes, and relatively uneven terrain. In the summer, it's problematic to get yourself around and in the winter, it's impossible.

The rugged environment of many northern Aboriginal communities forces many people with disabilities to stay in their homes. When and where they do venture outside, they may need to rely upon the assistance of a family member:

Interviewer: Do you find it hard to get around here?

Respondent: In the winter, it's too cold to go outside. In the summer, it's easy. I go next door.

Interviewer: How do you get there? It's up a hill, isn't it?

Respondent: I just go. But I need someone with me.

This need for assistance may or may not be considered a barrier to individual freedom. Individuals who have grown up in the north are likely accustomed to the challenges of the terrain and the environment. When a physical impairment may hinder their mobility, coping strategies seem to be a part of reality. No respondents during the course of this project complained excessively about the difficulties one had to face when living in a northern community with limited resources, nor was there any complaint of an unacceptable dependence upon others. The harsh realities of northern climates and terrain in isolated communities can perhaps explain the strength of this interdependent relationship.

7.2 COMMUNITY ACCESSIBILITY

Transportation

Eighteen northern Aboriginal communities in Manitoba have no road access other than a winter ice road, open two to three months a year. Travel for the remainder of the year is with motor boat or airplane. While air travel is a common reality in these isolated communities, a Sowiind EMB-110 air crash in northern Manitoba on December 9, 1997, has brought northern air safety under renewed scrutiny. This recent air crash, killing four and severely injuring two individuals, has brought public and political attention to the substandard air travel and emergency safety measures in many northern communities. Among the problems cited are a lack of approach lights, unpaved runways, no navigational aids such as radar, limited emergency equipment, and no minimum standards for the length of airstrips (Wild & Lowery, 1997). John Briggs, president of Ministic Air, has stated that in the recent air disaster, the airstrip was less than 925 meters long (Briggs as cited in Wild & Lowery, 1997). This compares to Ontario standards where airstrips are expected to be no less than 1,075 meters in length.

For individuals with impaired mobility, climbing in and out of a boat or an airplane is virtually impossible without complete assistance. Modified dock landings or airplane entrances for those with disabilities are not readily available. On January 1, 1994, changes to the *Air Transportation Regulations* required that air carriers covered by the regulations provide certain services and information to travellers with disabilities (National Transportation Agency of Canada, 1994). Yet certain limits to these regulations exist. They do not apply to Canadian air carriers with less than 30 seats; and an aircraft with less than 60 seats is not required to carry electric wheelchairs, scooters or manually operated

rigid-frame wheelchairs. They are only responsible for informing the passenger about other arrangements available to transport the aid. The majority of the aircraft servicing Manitoba's isolated Aboriginal communities have less than 30 seats and as such are not required to comply with accessibility regulations.

Public transportation, including that designed specifically for wheelchair users, does not exist in remote northern communities. Local transportation is provided through private means, generally by family and friends, or local entrepreneurs offering taxi-type services. Many communities provide medical transportation to the health centre or nursing station, but generally by conventional van only. Easy access to wheelchair accessible vehicles is rare. If a wheelchair van is purchased for a specific individual, there is no guarantee that it will not be used for the benefit of the general community at any given time (National Aboriginal Network on Disability, 1990).

Public Buildings

Public buildings, such as the nursing station or health centre and the band council offices, are encouraged to be wheelchair accessible. Federal programmes to improve community access have been initiated with mixed results. The Department of National Health and Welfare, now Health Canada, as part of the 1991 National Strategy for the Integration of Persons with Disabilities, devoted \$2 million to improve access to health services on reserves by retro-fitting existing health facilities. The total costs necessary to renovate the 267 facilities requiring retro-fitting came to \$7.5 million (Standing Committee on Human Rights and the Status of Disabled Persons, 1993, p. 12). Eighty per cent of the facilities not renovated under the Strategy, were renovated only upon the approval by the Treasury Board.

Without mandated or legislated regulations, enforcement of accessibility provisions has been difficult if not impossible. Many of the privately-owned stores in Aboriginal communities continue to lack ramped entrances or automated doorways for easy wheelchair accessibility. Recreational buildings and leisure programmes are generally designed for the able-bodied only, ignoring those with mobility, hearing, visual or cognitive impairments. Where the infrastructure of a community does not consider the unique needs of all its citizens, members may feel isolated and excluded:

Interviewer: Do you have any problems getting into the Band office?

Respondent: I never go to the Band office.

Interviewer: Before you had your accident, did you go to the Band office?

Respondent: Yeah.

Interviewer: How come you don't go now then?

Respondent: No transportation.

Interviewer: So, if there were transportation around, would you go?

Respondent: I would try.

7.3 HOUSING

According to the Canadian Medical Association (1994, p. 33), housing and infrastructure can be linked to issues of population health. The quality of housing may be a marker of existing socioeconomic circumstances and poverty. The following probable relationships have been identified (Table 4):

Table 4
Health Problems Associated with Housing Quality

Housing Aspect	Associated Problem
Crowding	Infections <ul style="list-style-type: none"> • respiratory • skin and eye • tuberculosis • meningitis • measles Injuries Mental Health <ul style="list-style-type: none"> • homicides and violence
Disrepair	Injuries
Water and Sewage	Gastroenteritis Skin Infection
Indoor Air Quality <ul style="list-style-type: none"> • wood stoves • cigarette smoke 	Respiratory Symptoms
Cleanliness	Respiratory; moulds and dust
Safety <ul style="list-style-type: none"> • no electricity; use of candles, kerosene lamps • appliances • faulty wiring 	Fires

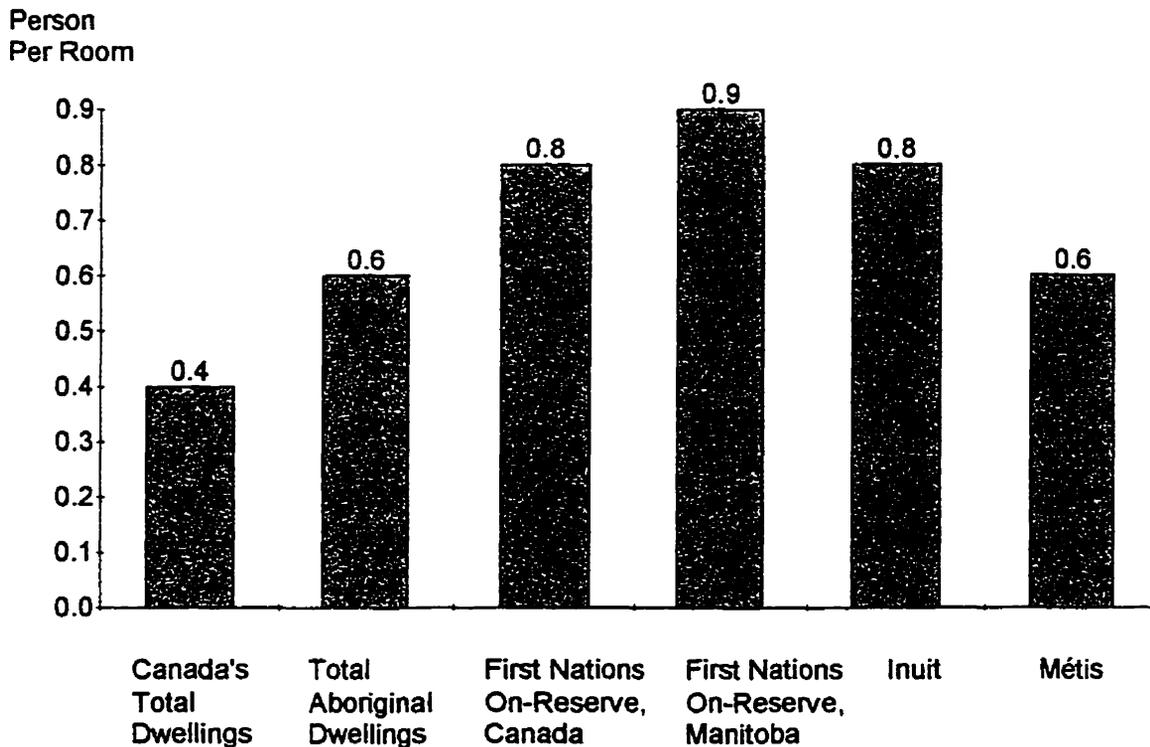
(Young, 1991, as cited in CMA, 1994, p. 34)

Issues such as crowding, safety, air, and water quality are common in many northern Aboriginal communities. An examination of housing standards on

reserve in Canada may partially explain the high prevalence of disability among Canada's Aboriginal peoples.

The 1991 *Aboriginal Peoples Survey* (Statistics Canada, 1994a) reported overcrowding and safety issues as primary concerns regarding housing on reserve in Canada. Figure 13 depicts the overcrowded housing conditions in Aboriginal communities compared to Canada as a whole.

Figure 13
Crowding, Canadian Housing, 1991



(Statistics Canada, 1994a, p. 6, and 1994b, pp. 58,94,95,130,154)

In 1991, the average Canadian home had 0.4 persons per room (Statistics Canada, 1994a, p. 6). Among the Aboriginal groups, overcrowding

was twice the national rate in Inuit dwellings and in dwellings on Indian reserves and settlements, with an average of 0.8 persons per room. But the highest rates of overcrowding for First Nations living on reserve in Canada can be found in Manitoba and in Saskatchewan (not shown), where the average number of persons per room is 0.9 (Statistics Canada, 1994b, p. 95).

Table 5 lists the various housing characteristics reported in 1991. While 32% of Canadian homes required either minor or major repairs, 49% of Aboriginal homes overall in Canada were in need of similar repair (Statistics Canada, 1994a, p. 6). The number rises even further on reserve, where 68% of homes reported a need of minor or major repairs. In Manitoba, 70% of occupied dwellings on reserve reported need of repair (Statistics Canada, 1994b, p. 101). This state of disrepair is in spite of the year of construction. The greatest proportion of homes built in Canada since 1971 is on-reserve (79%), followed by Inuit (69%), and Métis (53%), compared to Canadian dwellings as a whole (46%) (Statistics Canada, 1994a, p. 5).

The presence of bathroom facilities was reported by 83% of homes on Canadian First Nations reserves and settlements, compared to 99% in the rest of Canada (Statistics Canada, 1994a, p. 7). This compares to 73% of homes on reserve in Manitoba (Statistics Canada, 1994b, p. 99). Twenty-two per cent of homes on reserve in Canada use outhouses (p. 100), compared to 43% of homes on reserve in Manitoba (p. 101). Available water is considered unsuitable for drinking in 20% of Canadian Aboriginal homes overall (p. 60). This proportion rises to 24% in First Nations reserves in Canada overall (p. 96). Manitoba's First Nations dwellings on-reserve are similar to the Canadian Aboriginal average, that is 20% consider their water unsuitable for drinking (p.

97). Many people, however, are still forced to obtain their water from nearby lakes and rivers, or have it trucked in.

Table 5
Dwelling Characteristics, Canada, 1991

	Canada's Total Dwellings	Total Aboriginal Dwellings	First Nations On-Reserve, Canada	First Nations On-Reserve, Manitoba	Inuit	Métis
			%			
Requiring Repair	31.8	49.1	67.5	69.8	42.5	47.1
Electric Heating	29.8	31.9	42.3	60	16	27.7
Wood Stoves	4.4	17.2	41.3	41.2	9.7	13.8
Bathrooms	99.4	91.2	83.4	72.9	96.3	93.4
Smoke Detectors	87.9	77.6	63.3	52	89.6	80.6
Fire Extinguishers	46.3	44.0	37.9	27.8	75.7	43.0

(Statistics Canada, 1994a, pp. 6-7, and 1994b, pp. 99-103)

In Manitoba, 46% of First Nation reserve residents reported in 1991 that their drinking water was trucked in, while 19% purchased their drinking water at a store (p. 97).

Overall, 93% of Aboriginal homes in Canada have electricity and 94% have heating systems (Statistics Canada, 1994b, pp. 60-62). Dwellings on Manitoba First Nations reserves reported no difference from the national Aboriginal average (pp. 97-99). The use of wood stoves was reported as the

main heating source in 41% of homes on reserve in Canada, as well as in Manitoba specifically (pp. 98, 99). This represents a tenfold difference from the Canadian average as a whole (Statistics Canada, 1994a, p. 7). These same dwellings on reserve also reported the lowest percentage of smoke detectors, 63% in Canada, and only 52% in Manitoba (Statistics Canada, 1994b, pp. 102-103). Only 43% of these same homes in Manitoba could report that their smoke detectors were in working order (p. 103). This compares to a overall national average of 87.9% (Statistics Canada, 1994a, p. 7). The presence of fire extinguishers was reported by 38% of First Nations homes on reserve, compared to 46.3% nationally (p. 7). Twenty-eight per cent of Manitoba on reserve homes, in comparison, reported the presence of a fire extinguisher, but only 21% reported them to be in working order (Statistics Canada, 1994b, p. 103). Inuit dwellings on the other hand, reported a 90% use in smoke detectors and a 76% use in fire extinguishers (Statistics Canada, 1994a, p. 7). This disparity between Aboriginal peoples can be explained by different regional building codes and the extent to which they are enforced.

Housing on-reserves in Canada is generally funded through the federal government. Nonetheless, homes are owned and maintained by the local band council. A list of housing needs is monitored by the band councillor responsible for housing and homes are provided through a process of prioritization. First Nations individuals requiring modifications to a home to make it more accessible must contend with other band members who are equally anxious to have their own housing needs met. In 1991, 17% of First Nations people living on reserve in Manitoba reported that they were on a waiting list for housing (Statistics Canada, 1994b, p. 103). In 1991, 460 Aboriginal persons reporting a disability overall in Manitoba required specialized features to enter, leave, or move about

their residence (p. 7). On First Nations reserves in Manitoba, 220 adults required similar features (p. 25). A need for access ramps or a ground level entrance was reported by 350 Aboriginal adults in Manitoba, 175 of whom were First Nations adults living on reserve (pp. 7, 25). Widened doorways were reported to be a need by 170 Aboriginal adults in Manitoba overall, and by 35 First Nations adults living on Manitoba reserves (pp. 7, 25).

For wheelchair users, ramps and widened doorways can represent the freedom to participate equally in family and community events. Where homes are without electrical heating, individuals with limited function must rely upon the goodwill of family or community members to assist in obtaining and preparing the wood for heating their homes. Individuals can wait for more than a year to obtain home modifications to overcome these environmental barriers, in spite of correspondence citing medical necessity.

The wife of one gentleman who had been home approximately six months following a severe stroke, described the impact of the housing conditions on their mobility on the reserve:

Interpreter: She wasn't prepared to come home because of the cold weather. Because she couldn't get the wood; she couldn't cut the wood. It was too cold and he was in pampers when he got out of the hospital.

Interviewer: What other kind of problems did they face when they got home?

Interpreter: Transportation. Like to go somewhere. She says that they stay home all the time.

Interviewer: How often has he been out?

Interpreter: Twice.

Interviewer: What about getting in and out of their house? Any problems?

Interpreter: He says that the boys lift him up to take him outside.

Interviewer: Does that bother him? Does he wish that he could do it himself? Or is he happy with that?

Interpreter: He says that he doesn't mind. In the summertime, they sit outside by the riverbank.

Another key informant described the following situation and the barriers faced by one visually impaired individual:

Blind people, they can't live in the community, because it's so uneven. If you have to go outside to the washroom, you have to tie a rope. And the kids play all kinds of things...

I remember one lady I went to visit, to talk to her, to see how she made out. 'Oh, I get so scared', she said. 'Twice, I just about burned my house', she said. 'I turned the thing on, I don't know if it's boiling', that type of thing. So, it's really hard. 'And going to the washroom, where am I going to go, when there's no running water inside? Am I going to go in the bucket? And I don't like that', she said. 'Cause I don't know if I'm going to make a mess, or I don't know if the door is closed, or if the window is open to let the air out', she said. 'What if somebody comes and visits me and my whole house smells like the toilet? You know, I can't go to the outhouse. My brother-in-law, one time,' she says, 'he put a string, a rope to the... it was a boardwalk, and I fell', she said. She fell on the boardwalk. She was really scared. So, she moved to Winnipeg.

One key informant working for a Manitoba tribal council explains the delay in home modifications as a result of limited band funds:

They don't have enough money for housing, for new kids that are getting married to have a brand new house. So, they put them in their mom's house. 'They have room'. They don't. I'm very sorry

to say that, but it's the truth. They don't have resources. Where would they get resources? They don't have disability funding. They don't have special... maybe a little bit special needs, but not... you know,...we're not supposed to be disabled.

The delay in home modifications may, however, also be related to a lack of awareness of the needs and rights of those with disabilities. Housing issues for people with disabilities have repeatedly been bandied back and forth between those responsible for health and those responsible for housing. The health sector states it is a matter of housing, not "health" per se. The housing contingent, on the other hand, views a special need related to a physical impairment as an issue of health. While accountability is argued back and forth, the individual with the special need goes without. One key First Nations informant involved in local political issues describes the problems around a lack of accountability and awareness, magnified by limited housing:

I was told that there are about three or four different floor plans of houses, none of which are particularly designed architecturally with people with disabilities in mind or with mobility impairments.

There is no policy right now as far as I know, that can make a community build an accessible house for somebody. You'd think that out of good consciousness, they're going to do that. When CMHC (Canadian Mortgage and Housing Corporation) has been asked why somebody's not getting an acceptable house, they're saying, well, that's not our responsibility; you know, we have our own standards for access. But the agreement that is made with the community, does not include enforcement of standards. They ultimately will decide how and who gets the house and what it's going to look like.

It's put to the community to ensure that that happens. And I think that sometimes it does; that it's getting better. If a person needs a house and you have a waiting list of twenty, thirty families waiting for a house, is there any priority given to a person in a wheelchair?

Probably not. Or there's no guarantee of it. That person has to wait like everybody else.

Subsidized funds for special housing projects do exist, but they are not widely communicated. Lack of communication between funding sources, the health care providers, the consumers, and the band councils magnifies the lack of consistency. The Residential Rehabilitation Assistance Program (RRAP) is a source of funding through the Canadian Mortgage and Housing Corporation (CMHC) that has been available since the late 1970s. The original programme was to assist in upgrading homes in terms of structure, plumbing, overcrowding, heating, health and safety. Up to \$18,000 (\$21,000 in northern communities) is obtainable per project, with a maximal forgivable loan of \$12,000 (CMHC, personal communication, March 24, 1998). Limited resources have contributed to significant waiting lists for this programme both in the city of Winnipeg, and the rural areas of Manitoba. The RRAP programme for the City of Winnipeg is administered directly by the CMHC, while in rural Manitoba the programme is managed by the Manitoba Métis Federation off-reserve. The portion of the RRAP budget earmarked specifically to homes on-reserve in Manitoba is distributed among the tribal councils, and administered by an appointed First Nation RRAP representative.

A Disabled component of the RRAP programme has been designed specifically for the modification of homes due to needs related to a disability. Available funding per project is similar to that of the RRAP programme (CMHC, personal communication, March 24, 1998). Requests for funding through the Disabled RRAP programme are granted through the RRAP agent of the relevant tribal council. This programme has been consistently scaled back over the last

several years due to fiscal restraints (CMHC, personal communication, March 24, 1998).

The Home Adaptations for Seniors Independence (HASI) programme represents another source of financial support for home renovations attainable through the Canadian Mortgage and Housing Corporation (CMHC). This programme is designed specifically for applicants over the age of 65, and provides a forgivable loan of up to \$2,500 per project. The HASI programme is available throughout the province of Manitoba, on-reserve as well as off-reserve.

A limited variety of resources exists through which First Nation communities can apply for special funding for housing modifications. Unfortunately, in those communities which are non-road accessible, the funds are quickly diminished by the high transportation costs of air freight or by winter road.

First Nations find themselves in a complex dilemma where requests for home modifications for persons with disabilities must be balanced with meeting general housing needs. Where poor housing standards may be a contributing factor to high rates of disability overall, decision-makers must consider the needs of the individual with an impairment within the wider context of the needs of the community as a whole. Persons with a disability may find their requests are overlooked. As long as accessibility policies are not enforced, people with disabilities must rely upon the good will and intentions of their elected officials. Where the structural environment has indeed been appropriately modified, persons must still face the inevitable barriers of a harsh terrain and climate. The magnitude of the obstacles may eventually leave the individual no alternative but to relocate to an urban setting, away from his or her own family, and cultural supports.

CHAPTER EIGHT: ASSISTIVE DEVICES

Assistive devices for people with disabilities are most often used 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 prevention of further deterioration. They can include such familiar items as eyeglasses and hearing aids, or limb braces, crutches or augmentative communication devices. An individual's quality of life can be affected by the gains achieved. In 1991, 24% of those Aboriginal people in Canada who reported a disability, reported the use of such specialized technical aids (Statistics Canada, March, 1994b, p. 2). This compares to 21% of Aboriginal people in Manitoba (p. 3), and 15% of those from First Nations specifically, living on reserve in Manitoba (p. 21).

Assistive devices are normally prescribed by a health care provider and funding for the equipment is variable in terms of source, amount, and frequency. Both short and long-term loans for certain equipment have been made available free-of-charge for the majority of Manitobans. The costs of medical equipment will often be absorbed by third party payers, for example Workers' Compensation, Autopac, and private health insurance. Many individuals must bear the financial burden of purchasing specialized equipment themselves, often at a time when they can least afford the additional expense.

Many of these devices are available under the Non-Insured Health Benefits Programme for those Aboriginal people considered eligible. For the providers and prescribers, however, the process can prove to be quite complicated. Decisions regarding equipment provision and eligibility are often

made without any explanation to the prescriber. Two different types of devices will be highlighted to explore apparent trends in this service.

8.1 MOBILITY AIDS

Aids for mobility, including wheelchairs, motorized scooters, walkers, crutches and canes can offer an individual the ability to move safely and independently from one location to another. They can be used to manage a variety of impairments such as poor balance, healing of broken limbs, lower limb paralysis, amputation of lower limbs, and severe arthritis. The use of specialized aids, equipment or systems for mobility or agility was reported by 9,335 Aboriginal persons in Canada in the 1991 *Aboriginal Peoples Survey* (Statistics Canada, March, 1994b, p. 2). This represents 8% of those individuals who reported a disability. In Manitoba, 6% of Aboriginal persons overall who reported a disability, also reported the use of such specialized equipment (p. 3). A similar proportion was reported by those persons from First Nations living on-reserve in Manitoba (p. 21).

Devices to help with walking, such as walkers, crutches and canes, are available to all Manitobans on loan for up to three months from the Canadian Red Cross. Return of the equipment, including postage, is the responsibility of the user. For equipment required longer than three months, the Society for Manitobans with Disabilities (SMD) provides similar equipment for an indefinite loan period. Those Aboriginal persons eligible for Non-Insured Health Benefits (NIHB) who require the long-term use of such equipment have the item purchased on their behalf by Medical Services.

Walking aids are designed for flat terrain only and are unable to accommodate to uneven surfaces. As discussed in Chapter Seven, people may remain house-bound out of fear of falling, particularly in rural areas. It is another reason why many persons with disabilities from remote northern communities

choose to relocate to Winnipeg, where sidewalks are paved and generally well maintained.

Manual or standard wheelchairs are provided in Manitoba by the Society for Manitobans with Disabilities (SMD) for an indefinite loan period. Motorized wheelchairs and special cushions to prevent skin breakdown must be purchased privately. For those eligible Aboriginal persons, standard wheelchairs are purchased from SMD through the Medical Services Branch (MSB), under the Non-Insured Health Benefits (NIHB) programme. MSB wheelchairs are also considered to be an indefinite loan and are to be returned to the MSB equipment pool for redistribution when no longer required. Wheelchair provision is limited in frequency to once every five years; wheelchair maintenance is provided free-of-charge by SMD.

To process the wheelchair acquisition, SMD requires a completed request form with a physician's signature, which it then forwards to the NIHB unit for approval. A variety of wheelchair designs are available, the majority of which are geared towards the home or urban setting, or specifically for sports. All-terrain wheelchairs suitable to the rural and rugged conditions of some Aboriginal communities are rare. Given the environmental factors, a five year limitation for replacement is not always realistic in these communities. A physiotherapist working in northern Manitoba describes the demands placed on a standard wheelchair:

The wheelchairs get beaten up fairly quickly up there. The fact (is) that if people are using them outside at all, they are using them on a much rougher terrain. Perhaps there is a little less care taken of them and sometimes a little neglect on the part of the client, but it's often just a reflection of the realities of life. If you are going to live in a relatively small and crowded house, even if your wheelchair is

folded, it's not going to be stored in your living-room, where it's in the way. It's going to be out in the woodshed perhaps.

And the cold is going to take its toll on the plastic pieces and the rubber pieces and the tires to some extent. It's going to be folded and unfolded a lot more because you can't manage that way. It may be carried up and down steps because you don't have an appropriate ramp. Where you don't have paving, you have a lot more dust and you have a lot more wear and tear on axles and bearings and such things. I don't think there's anything very practical available commercially.

Motorized or electric wheelchairs are not a benefit under the NIHB programme and are considered on an exception basis only. Medical justification by the physician and occupational or physical therapist is necessary before MSB will consider the request. After a series of exception control record and equipment request forms, the medical consultant for MSB-NIHB determines final approval. A decision generally takes several months to obtain. In spite of recommendation by the individual's physician and therapist, denials of equipment are common. A health care provider working both in northern communities and in an urban setting, describes her frustration with the current process:

There's not, in my experience, a lot of written criteria as to why something would be denied or approved. It's just kind of a judgement call on the part of whoever they happen to have at the time.

It's an inequity because the end result of it, is that, yes, a person has treaty status and you apply for a power chair for them, and they are living off-reserve, they will get it. But if they are living on reserve, they will not get it if MSB refuses it. Because I've been told by Wheelchair Services in the case of a fellow that I had refused, (in spite of the provincial Wheelchair Services panel approval) that if he were living off reserve, and MSB refused it, then the provincial program would have picked it up. It's an

inequity in terms of, if you're going to use this program, the panelling procedure, why are you differentiating between treaty and non-treaty people? It's also an inequity geographically. If this fellow had been living in Winnipeg, he'd be sitting in that chair.

Now if he was non-treaty and living on that reserve, which was the case up until five years ago...he was non-treaty because his mother lost her treaty status when she married. If I'd applied for that chair five years ago, he would have got it on- or off-reserve, because he would have been non-treaty status and a provincial responsibility!

Valuable resources in terms of health care workers' time and effort are needlessly used in attempting to complete otherwise simple requests. As long as jurisdictional disputes continue over responsibility for funding, individuals who require assistive items risk going without.

8.2 ORTHOTICS

Orthotics can provide biomechanical support for weak joints due to muscular, skeletal or ligamentous damage. They can facilitate someone's function by making an activity less painful or less energy-demanding. Orthotics generally include braces, splints, arch supports, and shoe modifications. Braces and splints required for daily use are generally paid for by provincial health plans. Shoe modifications or inserts, on the other hand, are not normally covered by provincial health plans, but are included in some third party health insurance plans.

Orthotics are a benefit under the Non-Insured Health Benefits (NIHB) programme of the Medical Services Branch. NIHB will cover the cost of the device with a physician's prescription, generally twice in a two year period for foot orthotics, and once every two years for other upper or lower limb orthotics.

Footwear, in particular, has become a contentious issue over the last several years. Until early 1995, MSB-NIHB covered the cost of special footwear in Manitoba, such as extra-depth shoes. People who have diabetes and/or circulatory problems in their feet, or arthritic deformities are at high risk of abnormally painful feet, skin breakdown, and ulcerations. Ulcerations may often lead to an invasive infection, such as osteomyelitis, which may in turn require an eventual amputation of the affected limb. Extra-depth shoes to accommodate abnormal feet with poor circulation are seen as a preventative measure. MSB, without any prior warning to health care providers or vendors, discontinued this benefit in Manitoba in early 1995. They stated that this service was never part of the initial mandate. They did, however, continue to provide extra-depth shoes for those persons with diabetes. Commercially-manufactured, extra-depth footwear for people with diabetes at a cost of approximately \$200.00 seemed

minimal when compared to the economic impact of limb amputation, both for the individual and the health care system. This benefit was then also discontinued as of November, 1995. MSB states that non-custom orthopaedic footwear was never its responsibility. Only custom-made shoes for those feet which cannot be accommodated by conventional shoes are a benefit under NIHB (Manitoba Regional NIHB Manager, MSB, Information Bulletin No. 14, October 30, 1995). Custom-made shoes are modelled from plaster casts and sent out of province for manufacturing, costing upwards of \$1,000. Health care providers may find now that custom-made footwear is the only viable option. In communities where unemployment rates are staggering and local stores offer very few choices in terms of expense and design of footwear, suitable and affordable shoes may not be available locally. Where appropriate footwear is not provided in a timely fashion, any immediate savings may be at the eventual expense of the individual's health and the health care system as a whole. A key informant who provides health services to a remote community describes the reality of the situation:

Now if I want to put specialized shoes on somebody to protect their feet, the only option I have is to try and get them to fit into the criteria for specially built shoes, which is going to cost anywhere from \$700 to \$1500, when quite often they would be quite adequately shod with a pair of over-the-counter shoes and modifications and the total cost would be \$250. I agree if you look very closely at the criteria, this is not an expensive item. But it's a lot cheaper than buying artificial legs. Make your criteria as firm as you can, but, you know, don't cut off options in the interest of cost cutting when it may cost you more down the line.

It looks to me as though what's happening is that individual budgetary lines are being cut back by people who don't have responsibility for the total costs. Quite often they cut back small budget lines and they save money in the budget lines, and they

may increase costs somewhere else. Nobody's looking at that as far as I can tell. I have a lot of concerns about that kind of thing.

It should be noted, that these recent changes in the form of cutbacks and increased stringency with rules are simultaneously taking place during discussions around transfer arrangements to community control of health services. Critics feel that these changes are merely cost-saving measures to reduce the overall transfer payments to the communities.

The efficacy of any assistive technology must be predetermined by careful consideration of the context within which the item will be utilized. The type of device made available to individuals depends upon their own knowledge of equipment, eligibility for funding and appropriate assessments by rehabilitation specialists. The final decision regarding entitlement of special devices for individuals from First Nations then rests with the policy analysts and those who implement it. The complexity and ambiguities in the decision-making process leaves suppliers, prescribers and ultimately the consumers confused and disheartened.

CHAPTER NINE: CURRENT POLITICAL TRENDS

The multiple obstacles facing First Nations people with disabilities living in Manitoba do not exist in political isolation. As part of a larger First Nations community, they are part of a growing trend away from a centralized government authority towards a process of Aboriginal self-government. An understanding of what this new infrastructure will mean for the various communities is slowly emerging throughout the movement towards self-determination. In the province of Manitoba, these changes are occurring simultaneously with a major reorganization of the health care infrastructure, the speed of which has surpassed the process of self-government. As long as the health care of Canadians falls under provincial jurisdiction, provincial initiatives will influence Aboriginal health care, whether directly or not. The changes may only be evident off-reserve initially, but the potential to have wide-sweeping effects across the province must be accepted. Policy changes could improve equity of access and more appropriate need-based service utilization, but only where the political will is present and sufficient advocacy is demanding parity. Aboriginal health care delivery does not operate within a vacuum. The political trends in Manitoba and across Canada can have a longlasting impact on the health of Canadian Aboriginal people, but efforts must be made to ensure a positive outcome. This effort begins with a comprehensive understanding of the changes taking place.

9.1 Self-Determination for First Nations

Self-government for Canada's Aboriginal peoples is a process which continues to evolve. It represents a concept without definitive parameters and an on-going struggle between the Canadian federal government and its indigenous peoples. Aboriginal people assert that self-government is a right which their ancestors never relinquished. Former Grand Chief of the Assembly of Manitoba Chiefs, Phil Fontaine, has stated:

There's one right that we have - a right that belongs to all people of the world - and that's the right to govern ourselves.

People are just so completely tired and fed up with the intolerable conditions that we find ourselves in. The old way doesn't work - we need a new and different way of doing things. (as cited in Brodbeck, 1995, p. 6)

Future self-determination agreements may significantly change the administration and management of current services for their people. The impact these changes will have is only speculative at present but the expected outcomes are generally optimistic. The potential influence of self-government on the general health status of Aboriginal populations, for instance, has been considered by O'Neil and Postl (1994):

Self-government is a foundation for social development, and social development will contribute to improved health by supporting the healing process that is already under way in many Aboriginal communities. Therefore, self-government will affect not only the administration of services, but also the general well-being of Aboriginal populations. (p. 67)

Self-government is grounded in the traditional values of the Aboriginal Peoples, and it promotes social, political, and cultural development. Traditional health networks will be fostered under

self-government, and the policy-setting agenda for health will no longer be set externally. This rebalancing of the system in favour of Aboriginal values will lead to empowerment and to improvements in self-esteem for those working within the system, as well as for those served by it. Improvements in health will result from the self-esteem and empowerment that self-government brings about. (p. 82)

Recognition of the wider determinants of health and well-being is growing. The influence of the physical environment upon health, in terms of air, soil and water pollutants is now widely accepted (Evans & Stoddard, 1990). Sociocultural networks and the personal support they can provide have been implicated in health status (Corin, 1994; North, Syme, Feeney, Head, Shipley & Marmot, 1993). A strong link has also been forged between health and poverty, the gap in income distribution, education, and employment (Evans, 1994; Haan, Kaplan & Camacho, 1987; Marmot, Kogevinas & Elston, 1987; Marmot, Rose, Shipley & Hamilton, 1978; Wilkins & Adams, 1983; Wilkinson, 1992). Postl (1997) has likened the connection between Aboriginal health status and socioeconomic issues to the layers of an onion:

Like the skin of an onion, these determinants of health are layered over historical determinants and antecedents that often contribute to the perpetuation of ill health. Jurisdictional uncertainties, residential schools and treaty-based health entitlements are all important examples. (p. 1665)

Universal programmes designed simultaneously for all of Canada's Aboriginal peoples cannot be expected to meet the unique demands of specific populations. Initiatives to gain local control of community resources and programming for Aboriginal people can target specific areas of socioeconomic growth and environmental development, thereby impacting long-term health

outcomes. Self-governing Aboriginal communities would have the opportunity to determine their own needs. They would be empowered to initiate, implement, coordinate and evaluate their own programmes.

Community development also necessitates the settlement of outstanding treaty land entitlement agreements and inherent control over local resources (Treaty and Aboriginal Rights and Research Centre of Manitoba, 1994). Provincial and private interests in treaty land natural resources have often threatened the advancement of treaty settlements. Further in-depth examination of health-related implications of treaty land entitlement is beyond the scope of this paper.

In the Federal Liberal Party's election platform in 1993, the Liberal Party promised to "act on the premise that the inherent right of self-government is an existing Aboriginal and treaty right" (Liberal Party of Canada, 1993, as cited in Hylton, 1994, p. 239). In *An Information Guide For Registered Indians* (DIAND, 1993), the former Minister of Indian Affairs and Northern Development, Hon. Ron Irwin, MP, supports Aboriginal self-determination and control of Aboriginal programmes:

The government encourages and supports the transfer of control of health programs to Native communities or to Indian and Inuit organizations. Financing for these services is provided by contribution and contract arrangements.

The objective of community self-government negotiations is to work out new and practical arrangements within the existing constitutional framework. It is an option for communities which want to replace the outdated provisions of the *Indian Act* with negotiated self-government agreements. These agreements would provide significantly more scope for Indian governments than is possible under the *Indian Act* and will be implemented through special legislation.

The community-based self-government process is not intended to replace the constitutional process. Any arrangements resulting from negotiations are without prejudice to treaty and Aboriginal rights and to the eventual outcome of constitutional discussions. (pp. 9,11)

Policy statements provided by the federal government as cited above lend optimism to the federal position in the transfer process.

Transfer initiatives in the health sector were introduced by the federal government in 1986. Four phases were introduced in the health transfer process. The initial phase consists of pre-transfer planning. This entails the establishment of a health committee, completion of a community needs assessment, and the organizing of a community health plan. The second phase involves the completion of the community health plan. This plan incorporates the community health needs, priorities and goals, as well as the mandatory programmes set out by Health Canada. These mandatory programmes include communicable disease management, environmental health, and emergency response. The third phase comprises transfer negotiations between Medical Services and the community, along with community ratification. The fourth and final phase is health transfer implementation. As of October, 1997, 52 communities in Manitoba were engaged in the health transfer process, 15 of which had already signed a Health Transfer Agreement (Assembly of Manitoba Chiefs [AMC] Health Secretariat & Manitoba Keewatinowi Okimakanak [MKO], Briefing Note, December 6, 1997, p. 2).

Self-Government and Disability Issues

The barriers faced currently by Aboriginal people with disabilities could be alleviated by creating their own system of participation in self-determination. Programmes and services managed for Aboriginal people with disabilities by Aboriginal people with disabilities is a clear possibility, given the flexibility of the self-government process. Aboriginal people with disabilities must be given the opportunity to determine their own future, just as other Aboriginal people have demanded such an opportunity for themselves. Doreen Demas, Project Coordinator for First Nations People with Disabilities at the Assembly of Manitoba Chiefs, likens self-government for Aboriginal people to self-determination for people living with disabilities everywhere:

Self-government is governing oneself, having control over one's affairs. I mean, it's not any different than what the independent living movement is asking for, or the disability community has been asking for, in terms of not only inclusion, but having some control or some say in what is done for them or on their behalf. People with disabilities living in our communities are in the same position.

Now, I agree that it's somewhat unrealistic for people to think that this transition of things to self-government is going to be an easy process. Obviously, there's going to be growing pains; we're going to make mistakes. But I say, having never done it before, fundamentally, if you believe that that's what you want, then that's what should happen. It's okay to be leery of it, but not so afraid that you don't want it to happen.

Self-government has many uncertainties and this may cause some anxiety for those individuals who feel disempowered before or during the process of negotiations. But Doreen Demas seems encouraged by the inclusion of disability issues to date:

In terms of how First Nations people with disabilities are going to be integrated into the local control process and self-government, I think very much is dependent on the will of the communities and the leadership to ensure that decisions are being made. If we're not there to ensure that they 'dot their i's' and 'cross their t's', we're going to probably end up on the outside like we have before. The one thing I think that gives us a glimmer of hope, in terms of how services are set up, is that at least we're involved in the actual planning of things. In the past, what we've been forced to do is comply and live under existing kinds of policies and systems which obviously were not designed with our needs in mind.

With the presence of people with disabilities advocating their rights during the process of self-government, the obstacles they face in trying to participate equally in their communities will only gain more recognition. Increased awareness can only lead to a reduction in disparity of overall access and services.

Concerns Over the Self-Government Process

While the concept of self-government for Canada's Aboriginal peoples is widely accepted, certain concerns over the negative elements of the transfer process have been raised. This scepticism has primarily revolved around the issues of financing and the political integrity of the federal government. Certain Aboriginal individuals have also highlighted their own concerns over equal and adequate representation in the self-determination process.

Community control of the administration of federal programmes was initially endorsed without simultaneous control of programme planning, implementation, and evaluation. Transfer negotiations are frequently overshadowed by conflict over the extent of future independence for the Aboriginal peoples. Critics of the negotiation process are sceptical of the long-

term benefits. They fear that, without adequate financing or prior training of individuals to implement new services, communities will be left in the unenviable position of "administering their own misery" (Assembly of First Nations, 1988, as cited in Speck, 1989, p. 206). Federal initiatives are felt to be driven more by financial concerns than political ideologies. Flexibility in any future financial structure is emphasized by Maslove and Dittburner (1994).

Appropriate fiscal arrangements are a crucial element in the success of Aboriginal self-government... Inflexible conditional transfers under the Indian Act will have to be converted to unconditional funding that will maximize the fiscal flexibility of emerging Aboriginal governments. (p. 159)

Limited transfer payments without flexible terms as proposed by the federal government will also impact upon service availability. Goods and services previously purchased en masse or in group contracts at a lower rate could become subject to cost increases when they are negotiated on a programme by programme basis. The purchase of medical services or special equipment at a higher price by individual communities may preclude further purchases. Recruitment and retention of health care workers has been a chronic problem in the provision of services in remote northern communities. Although the number of community members becoming trained professionals is rising, local communities will be faced with the burden of external staff recruitment and retention strategies themselves.

Current trends in the reduction of Medical Services Non Insured Health Benefits appear to many people to be a means for the federal government to reduce its costs before transfer agreements are finalized. The recently enforced limitations to goods and services do little to ensure feelings of trust in the

transfer process. The National Envelope System, introduced in February of 1995 by the federal government, limits expenditures on Aboriginal health through a yearly fixed percentage of fiscal years: 1995/96 - 6%; 1996/97 - 3%; 1997/98 - 3%; 1998/99 - 1%; 1999/2000 - 3% (AMC Health Secretariat & MKO, Briefing Note, December 6, 1997, p. 1).

As the First Nations population is growing almost eight times faster than the non-Aboriginal population, AMC and MKO are concerned that funding mechanisms will be insufficient to meet the rising health needs of its people (AMC Health Secretariat & MKO, Briefing Note, December 6, 1997).

The Manitoba First Nation healthcare system is undergoing dramatic changes and duress as the process of transfer continues at this "fast-tracked" pace. The untimely shifting coincides with the implementation of the National Envelope System creating more tension and pressures on an already weak system. **THESE GLARING FACTS ARE IN DIRECT CONTRADICTION TO THE ORIGINAL ENDORSEMENT THAT HEALTH TRANSFERS WERE TO OCCUR AT A PACE DETERMINED BY INDIVIDUAL CIRCUMSTANCES AND CAPACITY.** [bold print and capitalization from source] It should be noted that there has not been any evaluation of the Health Transfer Agreement process in Manitoba aside from briefings and reports provided by the health technicians supporting the Assembly of Manitoba Chiefs - Chiefs Health Committee. (p. 2)

Health Canada is using this National Envelope System as their platform to govern the funding formula to First Nations health care. The Chiefs-in-Assembly were so outraged with the imposed restrictions that they called for an immediate dissolution of any health transfer negotiations or agreements (AMC Health Secretariat & MKO, Briefing Note, December 6, 1997, p. 5).

Changes underway in the Non-Insured Health Benefits programme have also raised apprehension in the transfer process. The NIHB programme was

excluded from the initial negotiations surrounding transfer agreements, but has since been included in several pilot projects. Medical Services Branch has recently decided to remove two specific benefits from this programme into Community-Based Health Programs: medical transportation, which they have recently centralized, and Allied Health Services (chiropractic, physiotherapy, psychology, home nursing and other services which vary across the region). The specific motive behind these decisions is not clear, but it is assumed that they are simply cost-saving measures. Such changes during the negotiation process of health transfer agreements only add to the existing feelings of mistrust.

Certain First Nations groups have voiced their concerns with possible negative outcomes of self-determination and local control over resources without existing federal guide-lines. Few of the criticisms have been published to date, but they reflect on-going issues at a community level. Some of the issues are universally applicable, while others are specific to traditionally disenfranchised groups, such as women and people with disabilities.

Margaret Jackson (1994) argues that the traditional Aboriginal emphasis on the collective good threatens the rights of women or disenfranchised individuals. She recounts the tale of an eagle, who is equally dependent upon both wings for flight (p. 190). While both wings can act independently of one another, the body of life is suspended between the two and the contribution of both is required for the eagle to soar to the greatest heights. This metaphor was meant to display the relationship between men and women; it demonstrates the balance that can be found between the contributions of both. This representation could equally depict the relationship between those able-bodied

and those disabled. Full and equal recognition and utilization of all its members can assist a community in reaching its highest potential.

Jackson fears that the Assembly of First Nations' position of not wishing to entrench the *Canadian Charter of Rights and Freedoms* may jeopardize the rights of the individual (1994, p. 185). The traditional values of maintaining collective rights above all else could override any individual injustice or special need. Ms Jackson is referring specifically to Aboriginal women's rights and issues, but similar concerns can be raised for Aboriginal people with disabilities. Without equal rights and freedoms legally applicable to all persons, justification for limitations to certain rights may inadvertently develop. The legal right to full community participation, regardless of gender or ability, is otherwise not guaranteed. Without legal entrenchment, enforcement is impossible.

Current service delivery has been complicated by multiple levels of responsibility and accountability, as previously discussed. Local control over services, without complete autonomy, could potentially add on another such layer of bureaucracy. Conversely, if complete community autonomy is present, there is no guarantee that individual programmes will be coordinated and integrated any more effectively than is currently the situation. National programmes such as Affirmative Action for women or people with disabilities will not necessarily apply to autonomous self-governed communities. Universal standards to improve access for people with disabilities are also at risk. The continuation of these programmes will likely depend upon the awareness and moral obligation of individual leaders, as well as financial capacity.

The methods for prioritization of limited funds will be at the mercy of local community leaders if external guide-lines are not in place. Individual chiefs and their councils will have to choose between funding modifications to a home for a

band member with a disability for example, or attempting to tackle overcrowded housing. Dissatisfied band members may claim that resource distribution is unequal. The balance of power in small communities may predispose to perceptions or accusations of political patronage. The process of the Framework Agreement Initiative (FAI) project has already been criticized as "being top down" (Peterson, 1997, p. 1). The FAI process giving First Nations' people the opportunity to restore First Nations' government in Manitoba, is based on community consultation, but the process has not always been easy.

A recurring problem faced by the FAI project is the lack of community participation. In many communities only a handful of people attend community coordinator workshops. (Peterson, 1997, p. 1)

Exploring the many reasons why individuals from some First Nations may choose not to get involved in the process of self-government is beyond the scope of this study. However, the empowerment of individual community members is paramount to successful community development. Many of these issues can hopefully be avoided with proper accountability of leaders to their communities.

9.2 Provincial Regionalization of Health Services

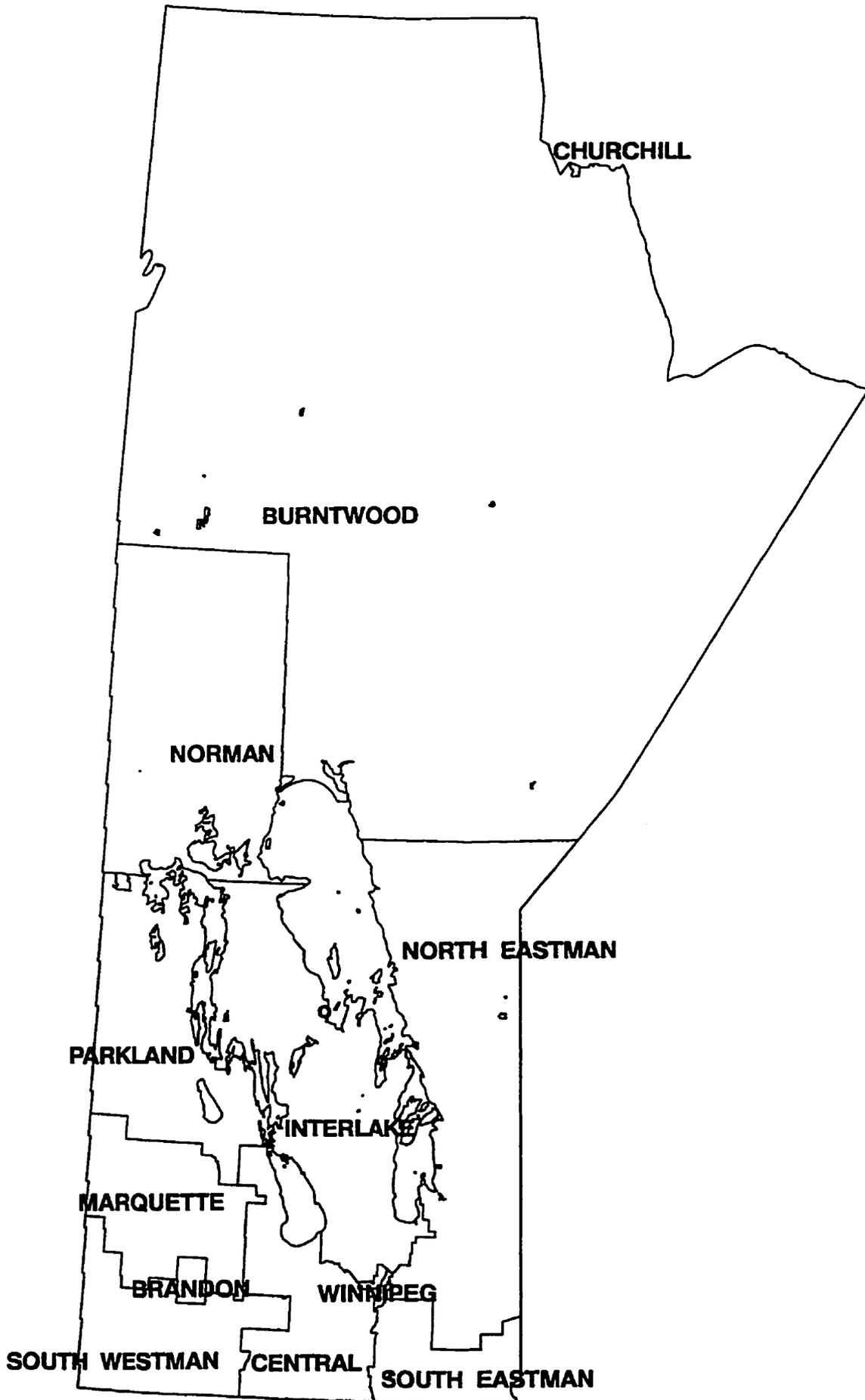
Regionalization in Canada has meant many things to many different people. It essentially implies a process of decentralization. Carrothers, Macdonald, Horne, Fish and Silver (1991) have defined it as follows:

The regionalization of health services in Canada embodies the selective application over time of concepts contained within its decentralization, geographic, and rationalization [underlining from source] dimensions by governments, agencies, and pressure groups responsible for the planning, financing and delivery of health and related social services. (p. 4)

Decentralization refers to the distribution of authority and power; geographic boundaries refers to social or political boundaries; and rationalization refers to the provision of a service at the least cost in terms of the use of society's scarce resources (pp.4-7). It should be recognized that these concepts may be subject to different interpretations by different stakeholders.

Regionalization is not a new concept. Already with the *Health Survey Grant* of 1948, the federal liberal government of Mackenzie King encouraged regional plans of health care organization (Taylor, 1987, pp. 163-164). Across Canada, there are currently numerous examples of provincial regionalization of health care, at varying stages of development and implementation. In Manitoba, the plan for regionalization of health services was first laid out in *Quality Health for Manitobans: The Action Plan* (Manitoba Health, 1992). Then Minister of Health, Don Orchard, called for a reduction in health status inequalities, increased efficiencies and flexibility and the promotion of alternative, less expensive health care service models. The new model envisioned a community-based focus, with improved continuity of care from institution to

Figure 14
Manitoba Health Regions, 1996



community, with distribution of services based on need and population health outcomes.

A reorganization of the health care system was first initiated in the northern and rural areas of Manitoba. Restructuring of the Winnipeg-based services was to follow on a two year time lag. Phase One of the Northern/Rural Health Association implementation plan was the development of boundaries. The Northern/Rural Health Advisory Council, established in 1992, accepted boundary proposals during the spring of 1993. After its review and an appeal process in 1993/94, ten northern/rural health associations were announced for the province in the fall of 1994. Figure 14 shows the various health associations or newly established health regions in Manitoba. Brandon was recognized for its size and the extent of its services by the establishment of its own Brandon Regional Health Authority.

Phase Two of the implementation plan was the development of a governance and organizational structure. It was acknowledged by the Northern/Rural Health Advisory Council that additional levels of bureaucracy and decision-making should be avoided. As such, the proposed model incorporated one body, with full authority over health services delivery within a region. Each of these new Regional Health Authorities (RHAs) would hire a Chief Executive Officer (CEO) and establish up to four District Health Councils (DHCs), which would act as advisory councils, not decision-making bodies. An RHA would be composed of up to 12 members elected from DHCs, two optional appointments by Manitoba Health, and one optional appointment by the RHA. Initial boards were to be appointed by December, 1995, with CEOs hired by February, 1996. A new funding formula was developed and available for testing by April, 1996, and the transfer of funds from Manitoba Health would begin April 1, 1997.

Manitoba Health documented its shift of service philosophy in its 1996 report *Next Steps: Pathways to a Healthy Manitoba* (1996), reproduced in Table 6.

Table 6
Fundamental Shifts in our Evolving Health System

From	To
• Treatment Orientation	• Socioeconomic determination of health orientation
• Institutional focus	• Institutional, community & home-based focus
• Boundaries	• Continuity of Care and Service
• Independent Organizations	• Integrated, Interdependent System
• Single Ministry	• Multi-Sectoral Approach
• Traditional Funding	• Alternative, Deliverables-Based Funding
• Professional Oriented	• Population Health/ Evidence Orientation

(adapted from Manitoba Health, 1996, p. 6)

The next phase of overall health care restructuring in Manitoba is the implementation of the Winnipeg Hospital Authority (WHA) and the Winnipeg Community and Long-Term Care Authority (WCA). Both of these authorities presently have their Chief Executive Officers in place. An important component of the reorganization of the WCA is the establishment of Neighbourhood Resource Networks (NRN). Manitoba Health has defined these networks as "an organizational framework for coordinating the delivery of health services and supporting community health and well-being" (Manitoba Health, 1997b, p. 1). Discussions around the integration of Winnipeg's existing community health

centres into the Neighbourhood Resource Network framework are currently underway, but the process is yet to be defined.

Provincial Regionalization and First Nations

Many First Nations have chosen not to involve themselves in what they have perceived as a provincial initiative. The federal government's role in Aboriginal health care has been well entrenched, whereas the provincial responsibilities have been elusive. This attitude has been apparent in the obvious absence of Aboriginal representation in the Regional Health Authorities to date, although this seems to be changing. Five of the ten current members of the Burntwood RHA, for example, are of Aboriginal descent (Neil Walker, BRHA Clinical Coordinator, personal communication, Oct 8, 1997).

While some First Nations may continue to feel that a provincial reorganization will not affect services on-reserve, they may need to consider the new funding mechanisms in place. Using total regional population data, including all First Nations communities, Manitoba Health has determined funding transfer agreements with the various RHAs. The RHAs will have the resources and the power to develop and allocate health care services throughout their region, including the redistribution of existing programmes according to perceived need. While this could fall in First Nations' favour with the addition of new and expanded programmes, it also depends on whose need is perceived as the largest. That will likely be influenced by who has the strongest advocacy. Shirley Ladd, Director of Rehabilitation Services for Community Therapy Services, has concerns regarding on-going physiotherapy programmes to First Nations under this new structure:

If we take a worst case scenario, and I used to never think this way, but I do now, if we take a worst case scenario, what can happen is that the money that provides the actual physiotherapy services, which is provincial dollars now, will be thrown into a pot in that region along with all of the other physio money, and then the region will make decisions about where that service is provided.

So if I take, and I guess my biggest concern, is the Burntwood region, because there is so little physio service in total in the region. If I take Burntwood region, you're looking at a situation right now, where I believe there are two physio positions actually funded to Thompson hospital, provincial positions. There may be some provincial funding to Churchill, and if there is, it would amount to less than 1.0 EFT. It's between .6 and .8 of an EFT. And then we have what amounts to .2 of an EFT, or one week a month in Norway House. There is no funded physio service in Lynn Lake and Leaf Rapids, and Gillam, which are all non-Aboriginal communities, with a small but kind of consistent industrial base. My concern is that the people on the boards of the Regional Health Authorities and responsible to make decisions about where the funds go will perceive that a community like Norway House, which is 90% Aboriginal, has considerably more service than Lynn Lake and Leaf Rapids, for instance. And so they will divert some of that service money. That's my concern. And that's the worst case scenario, but as far as I understand the situation now, there's nothing to say that that couldn't happen.

For the present, it seems that Medical Services is maintaining control of allied health services by moving them out of the Non-Insured Health Benefits Programme and into the Community-Based Health Programs. Manitoba Health, responsible for actual physiotherapy clinical funding on-reserve, has renewed its contract for the upcoming fiscal year 1998/99 with Community Therapy Services, as outlined in chapter five. In contrast, the RHAs are now in a position of choosing whether or not they would like to assume their own responsibility for rehabilitation service delivery. Brandon Regional Health Authority, for one, has opted to take on this responsibility itself. The other RHAs have either extended their contracts for another year or are in further negotiations. Nonetheless,

regionalization does have the potential to enhance services in First Nations communities regardless of location, if services are indeed redistributed according to need.

CHAPTER TEN: SUMMARY AND RECOMMENDATIONS

10.1 PRINCIPAL FINDINGS AND RECOMMENDATIONS

The prevalence of self-reported disability rates for Aboriginal peoples of Canada, as well as in Manitoba are twice that of the national average (Statistics Canada, 1994a,b). However, the allocation of resources to Manitoba First Nations communities does not reflect these health status disparities. The initial theoretical framework for the study (Figure 2) depicted the First Nations individual with a disability encompassed by a number of potential obstacles to independent living. The findings of the study have demonstrated the influence that existing external factors can play on the impact of these various obstacles on the individual.

Provincially funded support services to individuals with special needs are not available on-reserve, as the provision of these services is considered to be part of the federal government's mandate. Where programmes for people with disabilities do exist on-reserve, barriers to access are imposed by the scarcity of resources. Proactive measures to keep people with disabilities in First Nations communities appear limited by jurisdictional disputes and a lack of awareness of disability issues, both within and beyond community boundaries.

Rehabilitation Services

Current resources in Manitoba demonstrate disparities in service allocation in terms of physiotherapy, occupational therapy, and speech language pathology in light of the higher disability rates for Manitoba's First Nations population. Where available on-reserve, rehabilitation services are limited in

terms of quantity and type of therapy offered. In the former health region of Thompson in northern Manitoba, for example, the overall ratio of publicly funded physiotherapists to population in 1996 was one physiotherapist to 16,899 persons. In contrast, the similar ratio of physiotherapists dedicated specifically to First Nations communities in the same region was only one to 55,894 persons. None of the 18 First Nations communities without road access in Manitoba have any occupational therapy services in place. To receive vocational rehabilitation services, eligible individuals must establish a permanent residence outside of the reserve community. For extensive rehabilitation of any type, for example following a stroke, limb amputation or joint replacement, individuals are required to travel to urban settings, away from the support of family, friends and community.

Over the course of this study, individuals from First Nations who had received physiotherapy services within the previous two years appeared unable or unwilling to provide any type of critical analysis of the services that they had received. Potential reasons for this reluctance have been explored in terms of cultural norms of "non-interference". An alternative explanation may be that critical narratives may not be easily elicited from any former or existing patients. These same informants indicated that they did not play an active role in the process of setting their rehabilitation outcome goals. Language barriers may explain this lack of communication, although a group of physiotherapists reported the frequent use of trained interpreters. In contrast, the former recipients of rehabilitation interviewed in this project stated that trained interpreters were rarely present during the provision of services.

Key First Nation informants recommended that providers of rehabilitation services make greater use of visual aids in any patient teaching; encourage the

fuller usage of family members as available resources; and ensure greater continuity of care upon return to the community setting.

The narratives of physiotherapists working with First Nation clients, revealed limitations in communication as major obstacles in providing services. Communication barriers came not only in the form of language differences, but also specific cultural differences in the interpretation of illness and disability. Poor awareness in terms of the jurisdictional responsibilities for Aboriginal health care is identified as leading to practitioner frustration and ultimately discontinuity of care upon return of the individual to the community. Alternatively, the flexibility in clinical practice that physiotherapists may experience when working in isolated First Nations communities has also been explored.

The following recommendations in terms of rehabilitation services are based upon a critical analysis of the existing literature within the context provided by First Nation informants:

1. The allocation of physiotherapy, occupational therapy and speech language pathology services in Manitoba must reflect the needs of all Manitoba citizens, regardless of geographical or political boundaries.
2. Rehabilitation services must be provided in the community wherever possible, reducing the need for unnecessary travel to other centres by people with disabilities.
3. Rehabilitation programmes must reflect community demand for quality of services within the context of realistic resources. Careful consideration must be given to any alternative models of service delivery, such as the growing utilization of paraprofessionals in areas with limited resources.
4. Vocational rehabilitation programmes must be accessible throughout the province, regardless of geographical or political boundaries, and therefore prevent relocation to urban centres.

5. Advocacy on behalf of First Nations people with a variety of disabilities is strongly encouraged to achieve equitable access to rehabilitation services. Advocacy should be pursued ideally, but not exclusively, by persons from First Nations themselves.

6. Providers of rehabilitation services to persons from First Nations must be encouraged to observe culturally appropriate interventions, regardless of the location of service provision. This includes the consistent use of trained interpreters; appropriate adult education techniques; and the recognition of family members as valuable resources.

7. Providers of rehabilitation services to persons from First Nations must familiarize themselves with the jurisdictional, cultural and socioeconomic issues concerning provision of health services and benefits. This will facilitate both the coordination and assurance of continuity of services upon return to the community.

8. Post-secondary educational institutions are encouraged to enter into discussions with Aboriginal organizations to examine how they can increase the number of Aboriginal graduates from rehabilitation programmes. The programme curriculum should be modified so as to increase the cultural appropriateness and effectiveness of training provided to both Aboriginal and non-Aboriginal students. This issue is addressed by the Royal Commission on Aboriginal Peoples, Recommendation 3.3.16 (1996, p. 214).

Home Care

Manitoba is only one of two provinces in Canada which does not offer Home Care services on-reserve. The only support service available on Manitoba reserves is the homemaker programme, which falls far short of providing the trained personal care that many persons with disabilities require to remain in their homes. The reason for this disparity in service allocation is the provincial government's declaration that programmes on-reserve are a federal responsibility. In contrast, the federal government asserts that Home Care for all

provincial residents is a provincial responsibility, and that this is reflected in federal-provincial health cost-sharing arrangements.

The per capita expenditures on-reserve in Manitoba for support services for individuals with disabilities are only 48% of that for the off-reserve population (Health Canada, 1994, p. 44). Overall per capita hours of service per week are less on-reserve, as well as the hourly cost of such service provision. Existing services on-reserve have been criticized for an overall lack of integrated programming and the absence of standardized measurement tools to assess the supports required. Disparities in access to services are magnified by the absence of formally trained personal care attendants, case coordinators and dedicated Home Care nursing staff.

Persons from First Nations in Manitoba who require help for personal care, light housekeeping and meal preparation receive the greatest assistance from family members. Key informants in this study, while willing to assist family members, voiced their own limitations in providing the full extent of the support required. The additional responsibilities should not be minimized, given the reality of life in communities where the homes have no running water, are heated by wood stove, and are generally overcrowded.

It is recognized that the role of the caregiver may assume different dimensions in different cultures. Co-dependency relationships have been acknowledged as valuable means of reinforcing mutuality and unity both in family and community membership (Whyte & Ingstad, 1995, p. 12). But where there are no viable options, care is provided by family members out of necessity. Urban migration may however limit the availability of the extended family to share in this responsibility. Traditional models of caring for those who have special needs may not always be possible in the future.

The following recommendations in terms of Home Care services are based upon a critical analysis of the existing literature within the context provided by First Nation informants:

9. Home Care services must be equitable throughout Manitoba, in terms of access, training of personnel, and expenditures.

10. The provincial health care system must assume the fiscal responsibility of providing Home Care services on-reserve.

11. The design of on-reserve Home Care programmes must recognize the cultural and traditional models of caring.

12. Home Care services on-reserve should ideally be provided by First Nations persons for First Nations persons. Adequate funding must be provided for the appropriate training and remuneration of all required personnel.

Environmental Factors

The physical environment, both the structural and the natural aspects, has the ability to greatly impede an individual's ability to move freely from place to place. The unpaved roads, lack of sidewalks and the uneven terrain in many remote First Nations communities leave individuals with mobility or visual impairments extremely vulnerable to climatic conditions, such as snow and rain. Many people with disabilities find themselves forced to stay at home. While none of the participants in this study indicated dissatisfaction with personal mobility, their mobility was contingent upon the assistance of community and family members.

Public transportation in and out of the communities is primarily by airplane for 18 of Manitoba's First Nations communities. The accessibility guidelines for people with disabilities outlined in the *Air Transportation Regulations* apply to

Canadian air carriers with more than 30 seats. The majority of the aircraft providing scheduled service to remote First Nations communities in Manitoba however, has less than 30 seats and are therefore not required to meet the same standards of accessibility.

Local transportation in the majority of First Nations communities does not offer the type of accessible vehicle often found in urban settings. Participants in this study reported a change in their mobility patterns since the onset of their impairment, influenced by environmental barriers and the availability of accessible local transportation.

Public buildings on-reserve 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 will remain accessible to only a selected portion of the population, however, without the necessary funding or enforcement of accessibility regulations.

Poor housing conditions on-reserve are an on-going dilemma and may act as a contributing factor to high rates of disability overall. Decision-makers must consider the housing needs of the individual with an impairment within the wider context of the needs of the community as a whole. The specific priorities of the individual may thus conflict with the priorities of overall community development. As long as accessibility policies are not enforced and resources are scarce, persons with disabilities must rely upon the good will and intentions of their elected officials.

The following recommendations in terms of universal accessibility are based upon a critical analysis of the existing literature within the context provided by First Nation informants:

13. *Air Transportation Regulations* must be modified to enforce accessibility standards for all commercial aircraft providing scheduled service to First Nations communities.

14. All First Nations communities must be equipped with a wheelchair-accessible vehicle for the dedicated use of persons with disabilities. Accessible transportation must be available for medical appointments, social, and recreational events.

15. All buildings for public use on-reserve must be universally accessible. Adequate funding must be in place to facilitate this and the retrofitting of existing buildings where necessary. Enforcement strategies must be in place to monitor compliance with accessibility guidelines.

16. Housing codes on-reserve must be reviewed to determine whether they meet widely utilized accessibility guidelines. Adequate funding must be in place to facilitate this and the retrofitting of existing homes where necessary. Enforcement strategies must be in place to monitor compliance with accessibility guidelines.

Assistive Devices

Technology in the form of assistive devices for people with disabilities is most often used to enhance independence. Assistive devices may be used to facilitate functional activities, pain management or prevention of further deterioration. In 1991, 21% of those Aboriginal people in Manitoba, who reported a disability, reported the use of such specialized technical aids (Statistics Canada, March, 1994b, p. 3). Many of these devices are available under the Non-Insured Health Benefits (NIHB) programme for those Aboriginal

people considered eligible. The process and rationale of authorization for NIHB however, leaves many providers and prescribers confused and frustrated.

Many mobility aids and orthotics for example are assistive devices covered by NIHB with a medical prescription. Existing limits in the frequency of provision of these aids do not appear to consider the realities of a harsh northern lifestyle. Entitlement for replacement of walkers and wheelchairs, for instance, is limited to one device every five years. In communities where snow, mud and dust are a reality of everyday life, these limitations may not be realistic. Furthermore, these mobility aids are not designed for unpaved and uneven terrain. Options for more appropriate technological devices for this given environment either do not exist or are not part of the NIHB programme.

Trends in the provision of certain aids, such as motorized wheelchairs and orthotics, have been explored during the course of this study. Physiotherapists have voiced their concern over a lack of rationale provided in the decision-making process of eligibility for these devices. They have also noted that individuals with special needs seem to be the ones suffering the burden of current cost-saving measures.

The following recommendations in terms of assistive devices are based upon a critical analysis of the existing literature within the context provided by First Nation informants and the prescribers of these devices:

17. Limitations in the provision and authorization of assistive devices under the Non-Insured Health Benefits (NIHB) programme must consider the climatic conditions in which they are utilized. Frequency limits must be reviewed to reflect the realities of environments on-reserve.

18. A written explanation by Medical Services Branch must be forwarded to the prescriber where an individual's entitlement to special devices under NIHB has been refused.

19. Changes to the existing NIHB programme must be proposed only following consultation and consensus amongst providers and consumers.

10.2 SIGNIFICANCE OF THE STUDY

During this time of proposed transfer of Aboriginal health care responsibility from the federal government to individual Aboriginal groups, the findings of this study will have implications for both Aboriginal persons with disabilities and for those coordinating and providing rehabilitation services within this community. For the individual Aboriginal person with a disability, the findings could impact upon health care services, orderly and attendant care services, and access within his or her community. Local Aboriginal groups can use the findings to assist in appropriate community programme planning, implementation, and evaluation.

Occurring simultaneously with this reform in First Nations governing models, provincial health care delivery in Manitoba is rapidly undergoing its own changes. The decentralization process of health care to the various provincial regions has definite implications for First Nations around the province. The impact may be beneficial to First Nations or it may be detrimental. Without prior documentation of current services, however, changes will be difficult to monitor. This study should assist both those who are in positions of programme allocation, as well as future programme evaluation.

For the professional rehabilitation worker, the findings of this project offer a greater understanding of the obstacles faced by individuals from First Nations and the communities to which they return. The results may thus impact upon the direct care provided to these persons in a rehabilitation setting by reinforcing the need for cross-culturally sensitive delivery of health care services. This can be pursued through sensitivity training of our health care professionals, increased training of medical interpreters, and increased recruitment of Aboriginal people to work as health care professionals in their own communities.

Given Manitoba's diverse cultural population, the results of this study are of particular relevance to local communities and educational institutions. In this time of educational and health care funding restraints, it is crucial to the maintenance of these institutions that health care and social programming be both relevant and consumer-oriented. This project reflects such a focus.

10.3 CONCLUSIONS

While participatory research has the ability to empower those who partake, French and Swain (1997) point out that such research does not usually bring about policy change (p. 31). They do, however, acknowledge the influence that research can have on the climate of opinion. Many of the themes that have emerged during the course of this study are consistent with those of population health. The themes unique to the First Nations disability context underline the necessity for community-based services within an environment of overall socioeconomic development. The optimal health and social circumstances for a First Nations person with a disability cannot be achieved in isolation from the needs of the community as a whole.

The opportunity to participate equally in all aspects of community life is the benchmark of the disability consumer movement. The United Nations' *World Programme of Action Concerning Disabled Persons* (1983) clearly supports this philosophy and provides a basis from which progress may be evaluated:

Full participation in the basic units of society - family, social groups and community - is the essence of human experience. The right to equality of opportunity for such participation is set forth in the Universal Declaration of Human Rights and should apply to all people, including those with disabilities. In reality, however, disabled persons are often denied the opportunities of full participation in the activities of the socio-cultural system of which they are a part. This deprivation comes about through physical and social barriers that have evolved from ignorance, indifference and fear.

Attitudes and behaviour often lead to the exclusion of disabled persons from social and cultural life. People tend to avoid contact and personal relationships with those who are disabled. The pervasiveness of the prejudice and discrimination affecting disabled persons and the degree to which they are excluded from normal social intercourse produce psychological and social problems for many of them. (p. 20)

Equal participation for individuals with disabilities necessitates adequate community access to support services, be they medical, rehabilitative, technological or personal care. In her critical analysis of the concept of "community" within the context of disability, Lysack (1997) states that the answer to community-based rehabilitation "lies in efficient geographical dispersion of appropriate rehabilitation technologies" while for the independent living movement it lies in "personal empowerment and local control" (p. 232). She describes the potential challenges faced by both of these ideologies in communities considered not part of the industrialized affluent North.

In the South, IL (independent living) and CBR (community-based rehabilitation) both suffer from the deficiencies of top-heavy bureaucracies, elite control, communication problems, personal power struggles, restrictive organizational mandates, a fragmented population of individuals and organizations interested in community disability but holding very different agendas, a society generally unsure of its commitment to special needs groups, and finally a heterogeneous group of people with disabilities with diverse views on what constitutes appropriate disability services. (p. 232)

Lysack argues that without possessing a clear understanding of the concept of "community" neither approach has successfully emancipated people with disabilities from the institution and repatriated them to their rightful place in the community (p. 233). The concept of Community-Based Rehabilitation programmes is founded on the participation of volunteers. The feasibility of this model in First Nations communities warrants exploration. Any community-oriented service provision must adequately take the unique needs, expectations, and realistic resources into account. The process of service development and delivery must incorporate a clear commitment towards a coordinated effort at

meeting the needs of a cross-representation of people with a variety of disabilities.

Evans and Stoddart (1990, p. 1359) emphasize that "health policy as opposed to policies for *health care*" have to consider the balance between resources allocated directly to health care, and those to socioeconomic development in general. The international goal of equal participation for people with disabilities promoted by the United Nations (1983), encompasses such a framework of health and social issues:

The purpose of the World Programme of Action concerning Disabled Persons is to promote effective measures for prevention of disability, rehabilitation and the realization of the goals of "full participation" of disabled persons in social life and development, and of "equality". This means opportunities equal to those of the whole population and an equal share in the improvement in living conditions resulting from social and economic development. (p. 1)

Aboriginal self-government in Canada has the opportunity to incorporate this more holistic and comprehensive framework in its health and social policies. The final report of the Royal Commission on Aboriginal Peoples has identified four guide-lines for action concerning indigenous people's health (1996, p. 209):

1. *Equity* of health and social welfare outcomes.
2. *Holism* in the diagnosis of problems, their treatment and prevention.
3. Indigenous people's *control* over health systems.
4. *Diversity* in the design of systems and services.

Four strategies have been identified by the Royal Commission to achieve the restoration of healthy communities through community development (1996, p. 210):

1. The development of a system of Aboriginal healing centres and healing lodges under Aboriginal control as the prime units of holistic and culture-based health and wellness services.
2. The development of Aboriginal human resources compatible with the new system, its values and assumptions.
3. The full and active support of mainstream health and social service authorities and providers in meeting the health and healing goals of Aboriginal people.
4. The implementation of an Aboriginal community infrastructure development program to address the most immediate health threats in Aboriginal communities, including the provision of clean water, basic sanitation facilities, and safe housing.

The current study supports the above recommendations by the Royal Commission on Aboriginal Peoples. The strategies describe the necessary infrastructure, attitudes and acceptance of the broader determinants of health essential to the prevention of disability, rehabilitation and equal participation of all community members, regardless of ability. Aboriginal rehabilitation therapists could play an active role in any future Aboriginal healing centres as those described above.

The accountability and coordination of support services are clearly mandated to Aboriginal control within this framework. The inevitable complexities involved in the recruitment and retention of rehabilitation therapists in the community, while maintaining professional links with urban and academic counterparts must be recognized. The tripartite levels of government must share

the responsibility in ensuring that resources are adequately in place to allow the necessary allocation and dispersal of equitable services. Funding currently transferred to the Regional Health Authorities from Manitoba Health, should be proportionately under First Nations' control. With adequate funding and training, First Nations will be able to determine their own service needs and solutions. The equal participation of persons representing a variety of disabilities in the development and evaluation of health programmes and social services can ensure that a wide range of needs is considered in all activities.

Recurrent themes of empowerment and equal opportunities prevail discussions around both Aboriginal peoples and people with disabilities. The future leaders of Aboriginal self-government have a moral obligation to consider the issues raised by Aboriginal peoples with disabilities in all negotiations and decisions undertaken. Self-determination can become a reality for both the able-bodied and the disabled where there is an awareness and an enforcement of equal rights for all Aboriginal people. This approach would benefit not only those Aboriginal persons with disabilities, but all Aboriginal people equally.

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Appendix I
THE UNIVERSITY OF MANITOBA
Faculty of Medicine
Department of Community Health Sciences

FIRST NATIONS EXPERIENCE WITH DISABILITY
Community Information Sheet

This is a study on how service delivery presently works for First Nations people with disabilities. The project will examine the organization of the supports available to individuals with special needs, its strong points and weak points, and the perceptions of the people who use these support systems. The object of this research is to determine what obstacles are faced by those with disabilities at home and in the community. Issues around these barriers, eg. environmental, attitudinal, cost, accessibility to medical and rehabilitative care and responsibility for these services will be discussed in interviews between voluntary participants and the interviewer. The project fulfils the partial requirements of a Masters in Science degree in Community Health Sciences for the field researcher.

All the information shared will be kept strictly confidential and individuals and their communities will be kept anonymous. Individual names will not be used. The information will be reported in general terms to demonstrate what people feel about the current way they receive support. Volunteers have the right to refuse to participate without any effect upon the health care services they receive. If they do agree to participate, they can refuse to answer any questions they want. Participants are allowed to withdraw from the study at any time after they have signed consent. Again, this will have no effect on the health care that they receive. No promises of any added services or equipment will be made in exchange for participating. If it appears that an individual would benefit from the intervention of a certain health care provider, arrangements will be made to facilitate this process. Trained interpreters will be used in the interviews where language barriers exist.

The final report will belong to the communities involved. Before the final information is presented, the participants and/or representatives from their communities will have a chance to read the report and discuss any changes they think are necessary. All the volunteers involved will receive a final copy of the report. A presentation of the final results will be available for those communities who so wish.

This information will be useful to both the people who provide health care services for First Nations people with disabilities, and to those who organize this system. For those who are involved in program planning, implementation and evaluation, this study will provide some feedback about the current system of service delivery in operation.

Project Staff: Dr. Joseph Kaufert, Ph.D.
Ms. Moni Fricke, Master of Science student

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Appendix II
THE UNIVERSITY OF MANITOBA
Faculty of Medicine, Department of Community Health Sciences

FIRST NATIONS EXPERIENCE WITH DISABILITY
Volunteer Information Sheet

This is a study on the how service delivery presently works for First Nations people with disabilities. The study will examine the organization of the supports available to people with special needs, its strong points and weak points, and how people feel about these services who use them. The goal of this study is to look at what prevents people with disabilities from participating fully in their community, in spite of their disability, and what their experience has been like with rehabilitation services (physiotherapy in particular). The study is part of the researcher's work towards a Masters Degree in Community Health.

The reasons why people feel they are limited and what their feelings are about physiotherapy will be talked about in a one to two hour interview. The interview will take place wherever the volunteer feels most comfortable. The interview will be taped and the interviewer will be taking notes. That way, whatever is said will not be written down later in the wrong way. Interpreters will be used where language barriers exist.

All the information shared will be kept strictly confidential and individuals and their communities will be kept anonymous. Individual names will not be used. The information will be reported in a general way to show what people feel about the way they get services. While we hope you agree to participate, remember that your participation is all voluntary. You have the right to refuse to participate without any effect upon the health care services that you receive. If you do agree to participate, you can refuse to answer any questions that you want. You are also allowed to withdraw from the study at any time after you have signed consent. Again, this will have no effect on the health care that you receive. No promises of any added services or equipment can be made in exchange for volunteering. If it appears that you would benefit from a referral to a certain health care provider, arrangements will be made with you if you so wish.

The final report will belong to the people involved. Before the final information is presented, you will have a chance to read the report and talk about any changes you think are necessary. All the volunteers involved will receive a final copy of the report. A presentation of the final results will be available for those communities who so wish.

Your feedback through this study will be useful to both the people who provide health care services for First Nations people with disabilities, and to those who organize this system. For those who are involved in program planning, implementation and evaluation, this study will provide some feedback about the operation of the current system of service delivery.



Appendix III
FIRST NATIONS EXPERIENCE WITH DISABILITY

Volunteer Consent Form

I, _____, understand the goals of the First Nations Experience with Disability study, as explained to me by the researcher.

I agree to take part in this study. I understand that I can refuse to answer any questions or withdraw from the study at any time. I understand that everything I say will be treated as confidential and will only be used in a general way. Individual names will not be used. I have the right to refuse to participate without any effect upon the health care services that I receive. No promises of any added services or equipment can be made in exchange for volunteering. If it appears that I would benefit from a referral to a certain health care provider, arrangements will be made with me if I so wish.

The final report will belong to the people involved. Before the final information is presented, I shall have a chance to read the report and talk about any changes I think are necessary. All the volunteers involved will receive a final copy of the report. A presentation of the final results will be available for those communities who so wish.

Date: _____

Participant: _____

Investigator: _____

Appendix IV Interview Protocol

Format: semi-structured

Duration: one to two hours

Setting: chosen by the informant

Themes Guiding the Interview:

Potential Barriers to Independent Living

- attitudes of self, family, peers and community
- accessibility of community
- costs
- environmental barriers
- appropriateness of technological aids and adaptations, including mobility aids
- housing
- employment issues

Perceptions of the Current Structure of Service Delivery

- jurisdictional responsibility
- accessibility and availability of services
- medical and rehabilitative care
- role of the community
- benefits or available resources

Appendix V

Treaty Number Six

**Morris, 1880, reprinted 1991
Fifth House Publishers
Pages 351 - 355**

THE TREATIES OF CANADA
WITH
THE INDIANS OF MANITOBA
AND
THE NORTH-WEST TERRITORIES,
INCLUDING
THE NEGOTIATIONS ON WHICH THEY WERE BASED, AND
OTHER INFORMATION RELATING THERETO.

BY
THE HON. ALEXANDER MORRIS, P.C.,
LATE LIEUTENANT-GOVERNOR OF MANITOBA, THE NORTH-WEST TERRITORIES,
AND KEE-WA-TIN.

TORONTO :
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TO HIS EXCELLENCY

The Right Honorable the Earl of Dufferin,

*Her Britannic Majesty's Ambassador at St. Petersburg, K.P.P.O.,
K.C.B., G.C.M.G., &c., &c., &c.*

MY LORD,—

Encouraged by the earnest interest, your Lordship ever evinced, in the work of obtaining the alliance and promoting the welfare of the Indian tribes in the North-West of Canada, and in opening up the Territories for settlement, by obtaining the relinquishment of the natural title of the Indians to the lands of the Fertile Belt on fair and just terms, I have the honor, by your kind permission, to dedicate this collection of the treaties made with them, to your Excellency, in the belief that its publication will be timely, and that the information now supplied in a compact form, may prove of service to the Dominion of Canada.

I have the honor to be

Your Lordship's obedient servant,

ALEXANDER MORRIS,

Late Lieut.-Gov. of Manitoba, the North-West Territories, and Kee-wa-tin.

TORONTO, March, 1880.

Signed by the parties in the presence of the undersigned witnesses, the same having been first explained to the Indians by the Honorable James McKay:

(Signed) THOMAS HOWARD,
RODNERICK ROSS,
E. O. MORRIS,
A. G. JACQUES, M. D.
ALEXANDER MATHEWSON,
JOSEPH HOUNTON,
CHRISTINE V. K. MORRIS.

Memorandum.

The Queen's Indian Commissioners having met Thickfoot and a portion of the Islands band of Indians at Wapang or Dog Head Island, on the twenty-eighth day of September, A. D. 1875, request him to notify the Island Indians and those of Jack Head Point, to meet at Wapang an Indian agent next summer, to receive payments under the treaty which they have made with the Indians of Norway House, Berens River, Grand Rapids and Lake Winnipeg, and in which they are included, at a time of which they will be notified, and to be prepared then to designate their Chief and two Councilors. The Commissioners have agreed to give some of the Norway House Indians a reserve at Fisher Creek, and they will give land to the Island Indians at the same place.

Given at Wapang, this 23th day of September, A. D. 1875, under our hands.

ALEXANDER MORRIS,
Lieut.-Governor.
JAMES MCKAY.

I accept payments under the treaty for myself and those who may adhere to me, and accept the same and all its provisions, as a principal Indian, and agree to notify the Indians as above written.

Wapang, September 28th, 1875.

(Signed) THICKFOOT. His x mark.

Witness:
(Signed) THOMAS HOWARD,
RODNERICK ROSS.

NOTE.—In 1876 Messrs. Howard and Reid obtained the adhesions to the Winnipeg Treaty of the Indians of the Dog Head, Bloodvein River, Big Island, and Jack Fish Head bands on Lake Winnipeg, and of the Island and Grand Rapids of the Berens River band, and of the Pas, Cumberland and Moose Lake bands on the Saskatchewan River, as will be found stated in Chapter VIII.

THE TREATIES AT FORTS CARLTON AND PITT,
NUMBER SIX.

ARTICLES OF A TREATY made and concluded near Carlton, on the twenty-third day of August, and on the twenty-eighth day of said month, respectively, and near Fort Pitt on the ninth day of September, in the year of Our Lord one thousand eight hundred and seventy-six, between Her Most Gracious Majesty the Queen of Great Britain and Ireland, by her Commissioners, the Honorable Alexander Morris, Lieutenant-Governor of the Province of Manitoba and the North-West Territories, and the Honorable James McKay and the Honorable William Joseph Christie, of the one part, and the Plain and the Wood Cree Tribes of Indians, and the other Tribes of Indians, inhabitants of the country within the limits hereinafter defined and described, by their Chiefs, chosen and named as hereinafter mentioned, of the other part.

Whereas the Indians inhabiting the said country have, pursuant to an appointment made by the said Commissioners, been convened at meetings at Fort Carlton, Fort Pitt and Battle River, to deliberate upon certain matters of interest to Her Most Gracious Majesty, of the one part, and the said Indians of the other:

And whereas the said Indians have been notified and informed by Her Majesty's said Commissioners that it is the desire of Her Majesty to open up for settlement, immigration and such other purposes as to Her Majesty may seem meet, a tract of country, bounded and described as hereinafter mentioned, and to obtain the consent thereto of her Indian subjects inhabiting the said tract, and to make a treaty and arrange with them, so that there may be peace and good will between them and Her Majesty, and that they may know and be assured of what allowance they are to count upon and receive from Her Majesty's bounty and benevolence;

And whereas the Indians of the said tract, duly convened in council as aforesaid, and being requested by Her Majesty's Commissioners to name certain Chiefs and head men, who should be authorized, on their behalf, to conduct such negotiations and sign any treaty to be founded thereon, and to become responsible to Her Majesty for the faithful performance by their respective bands of such obligations as shall be assumed by them, the said Indians have thereupon named for that purpose, that is to say:—representing the Indians who make the treaty at Carlton, the several Chiefs and Councilors who have subscribed hereto, and representing the Indians who make the treaty at Fort Pitt, the several Chiefs and Councilors who have subscribed hereto;

And thereupon, in open council, the different bands having presented their Chiefs to the said Commissioners as the Chiefs and head men, for the purposes aforesaid, of the respective bands of Indians inhabiting the district hereinafter described;

And whereas the said Commissioners then and there received and acknowledged the persons so represented, as Chiefs and head men, for the purposes aforesaid, of the respective bands of Indians inhabiting the said district hereinafter described ;

And whereas the said Commissioners have proceeded to negotiate a treaty with the said Indians, and the same has been finally agreed upon and concluded as follows, that is to say :

The Plain and Wood Cree Tribes of Indians, and all other the Indians inhabiting the district hereinafter described and defined, do hereby cede, release, surrender and yield up to the Government of the Dominion of Canada for Her Majesty the Queen and her successors forever, all their rights, titles and privileges whatsoever, to the lands included within the following limits, that is to say :

Commencing at the mouth of the river emptying into the north-west angle of Cumberland Lake, thence westerly up the said river to the source thence on a straight line in a westerly direction to the head of Green Lake, thence northerly to the elbow in the Beaver River, thence down the said river northerly to a point twenty miles from the said elbow ; thence in a westerly direction, keeping on a line generally parallel with the said Beaver River (above the elbow), and about twenty miles distance therefrom, to the source of the said river ; thence northerly to the north-easterly point of the south shore of Red Deer Lake, continuing westerly along the said shore to the western limit thereof, and thence due west to the Athabaska River, thence up the said river, against the stream, to the Jasper House, in the Rocky Mountains ; thence on a course south-eastwardly, following the easterly range of the Mountains, to the source of the main branch of the Red Deer River ; thence down the said river, with the stream, to the junction therewith of the outlet of the river, being the outlet of the Buffalo Lake ; thence due east twenty miles ; thence on a straight line south-eastwardly to the mouth of the said Red Deer River on the South Branch of the Saskatchewan River ; thence eastwardly and northwardly, following on the boundaries of the tracts conceded by the several Treaties numbered Four and Five, to the place of beginning ;

And also all their rights, titles and privileges whatsoever, to all other lands, wherever situated, in the North-West Territories, or in any other Province or portion of Her Majesty's Dominions, situated and being within the Dominion of Canada ;

The tract comprised within the lines above described, embracing an area of one hundred and twenty-one thousand square miles, be the same more or less ;

To have and to hold the same to Her Majesty the Queen and her successors forever ;

And Her Majesty the Queen hereby agrees and undertakes to lay aside reserves for farming lands, due respect being had to lands at present cultivated by the said Indians, and other reserves for the benefit of the said

Indians, to be administered and dealt with for them by Her Majesty's Government of the Dominion of Canada, provided all such reserves shall not exceed in all one square mile for each family of five, or in that proportion for larger or smaller families, in manner following, that is to say :—

That the Chief Superintendent of Indian Affairs shall depute and send a suitable person to determine and set apart the reserves for each band, after consulting with the Indians thereof as to the locality which may be found to be most suitable for them ;

Provided, however, that Her Majesty reserves the right to deal with any settlers within the bounds of any lands reserved for any band as she shall deem fit, and also that the aforesaid reserves of land or any interest therein may be sold or otherwise disposed of by Her Majesty's Government for the use and benefit of the said Indians entitled thereto, with their consent first had and obtained ; and with a view to show the satisfaction of Her Majesty with the behavior and good conduct of her Indians, she hereby, through her Commissioners, makes them a present of twelve dollars for each man, woman and child belonging to the bands here represented, in extinguishment of all claims heretofore preferred ;

And further, Her Majesty agrees to maintain schools for instruction in such reserves hereby made, as to her Government of the Dominion of Canada may seem advisable, whenever the Indians of the reserve shall desire it ;

Her Majesty further agrees with her said Indians that within the boundary of Indian reserves, until otherwise determined by her Government of the Dominion of Canada, no intoxicating liquor shall be allowed to be introduced or sold, and all laws now in force or hereafter to be enacted to preserve her Indian subjects inhabiting the reserves or living elsewhere within her North-West Territories from the evil influence of the use of intoxicating liquors, shall be strictly enforced ;

Her Majesty further agrees with her said Indians that they, the said Indians, shall have right to pursue their avocations of hunting and fishing throughout the tract surrendered as hereinbefore described, subject to such regulations as may from time to time be made by her Government of her Dominion of Canada, and saving and excepting such tracts as may from time to time be required or taken up for settlement, mining, lumbering or other purposes by her said Government of the Dominion of Canada, or by any of the subjects thereof, duly authorized therefor, by the said Government ;

It is further agreed between Her Majesty and her said Indians, that such sections of the reserves above indicated as may at any time be required for public works or buildings of what nature soever, may be appropriated for that purpose by Her Majesty's Government of the Dominion of Canada, due compensation being made for the value of any improvements thereon ;

And further, that Her Majesty's Commissioners shall, as soon as possible after the execution of this treaty, cause to be taken, an accurate census of all the Indians inhabiting the tract above described, distributing them in

families, and shall in every year ensuing the date hereof, at some period in each year, to be duly notified to the Indians, and at a place or places to be appointed for that purpose, within the territories ceded, pay to each Indian person the sum of five dollars per head yearly :

It is further agreed between Her Majesty and the said Indians that the sum of fifteen hundred dollars per annum, shall be yearly and every year expended by Her Majesty in the purchase of ammunition and twine for nets for the use of the said Indians, in manner following, that is to say :—In the reasonable discretion as regards the distribution thereof, among the Indians inhabiting the several reserves, or otherwise included herein, of Her Majesty's Indian Agent having the supervision of this treaty :

It is further agreed between Her Majesty and the said Indians that the following articles shall be supplied to any band of the said Indians who are now cultivating the soil, or who shall hereafter commence to cultivate the land, that is to say :—Four hoes for every family actually cultivating, also two spades per family as aforesaid ; one plough for every three families as aforesaid, one harrow for every three families as aforesaid ; two scythes, and one whetstone and two hayforks and two reaping-hooks for every family as aforesaid ; and also two axes, and also one cross-cut saw, and also one hand-saw, one pit-saw, the necessary files, one griststone and one auger for each band ; and also for each Chief, for the use of his band, one chest of ordinary carpenter's tools ; also for each band, enough of wheat, barley, potatoes and oats to plant the land actually broken up for cultivation by such band ; also for each band, four oxen, one bull and six cows, also one boar and two sows, and one handmill when any band shall raise sufficient grain therefor ; all the aforesaid articles to be given *once for all* for the encouragement of the practice of agriculture among the Indians :

It is further agreed between Her Majesty and the said Indians, that each Chief, duly recognized as such, shall receive an annual salary of twenty-five dollars per annum ; and each subordinate officer, not exceeding four for each band, shall receive fifteen dollars per annum ; and each such Chief and subordinate officer as aforesaid, shall also receive, once every three years, a suitable suit of clothing, and each Chief shall receive, in recognition of the closing of the treaty, a suitable flag and medal, and also, as soon as convenient, one horse, harness and waggon :

That in the event hereafter of the Indians comprised within this treaty being overtaken by any pestilence, or by a general famine, the Queen, on being satisfied and certified thereof by her Indian Agent or Agents, will grant to the Indians assistance of such character and to such extent as her Chief Superintendent of Indian Affairs shall deem necessary and sufficient to relieve the Indians from the calamity that shall have befallen them ;

That during the next three years, after two or more of the reserves here- by agreed to be set apart to the Indians, shall have been agreed upon and surveyed, there shall be granted to the Indians included under the Chief's adhering to the treaty at Carlton, each spring, the sum of one thousand

dollars to be expended for them by Her Majesty's Indian Agents, in the purchase of provisions for the use of such of the band as are actually settled on the reserves and are engaged in cultivating the soil, to assist them in such cultivation ;

That a medicine chest shall be kept at the house of each Indian Agent for the use and benefit of the Indians, at the discretion of such Agent :

That with regard to the Indians included under the Chiefs adhering to the treaty at Fort Pitt, and to those under Chiefs within the treaty limits who may hereafter give their adhesion hereto (exclusively, however, of the Indians of the Carlton Region) there shall, during three years, after two or more reserves shall have been agreed upon and surveyed, be distributed each spring among the bands cultivating the soil on such reserves, by Her Majesty's Chief Indian Agent for this treaty in his discretion, a sum not exceeding one thousand dollars, in the purchase of provisions for the use of such members of the band as are actually settled on the reserves and engaged in the cultivation of the soil, to assist and encourage them in such cultivation ;

That, in lieu of waggons, if they desire it, and declare their option to that effect, there shall be given to each of the Chiefs adhering hereto, at Fort Pitt or elsewhere hereafter (exclusively of those in the Carlton District) in recognition of this treaty, so soon as the same can be conveniently transported, two carts, with iron bushings and tires ;

And the undersigned Chiefs, on their behalf, and on behalf of all other Indians inhabiting the tract within ceded, do hereby solemnly promise and engage to strictly observe this treaty, and also to conduct and behave themselves as good and loyal subjects of Her Majesty the Queen ;

They promise and engage that they will in all respects obey and abide by the law, and they will maintain peace and good order between each other, and also between themselves and other tribes of Indians, and between themselves and others of Her Majesty's subjects, whether Indians or whites, now inhabiting or hereafter to inhabit any part of the said ceded tracts, and that they will not molest the person or property of any inhabitant of such ceded tracts, or the property of Her Majesty the Queen, or interfere with or trouble any person passing or travelling through the said tracts or any part thereof ; and that they will aid and assist the officers of Her Majesty in bringing to justice and punishment any Indian offending against the stipulations of this treaty, or infringing the laws in force in the country so ceded.

In witness whereof, Her Majesty's said Commissioners and the said Indian Chiefs have hereunto subscribed and set their hands, at or near Fort Carlton, on the day and year aforesaid, and near Fort Pitt on the day above aforesaid.

(Signed) ALEXANDER MORRIS,
Lieut.-Governor, N.-W. T.

APPENDIX VI

Questions from the Health and Activity Limitation Survey (Statistics Canada, November, 1994)

Q. C1: Who usually prepares your meals?

- yourself alone
- yourself and someone else
- someone else

Q. C2: Is this because of your condition or health problem?

Q. C3: Who helps prepare your meals?

- | | |
|-----------------------------|--|
| i) Husband, wife or partner | vi) Other relative |
| ii) Son | vii) Friend or neighbour |
| iii) Daughter | viii) Voluntary organization or agency |
| iv) Parent | ix) Private organization or agency |
| v) Brother or sister | |

Q. C5: Because of your condition, do you need help or ADDITIONAL help in preparing your meals?

Q. C11: Who usually does your normal everyday housework such as dusting, tidying up?

- yourself alone
- yourself and someone else
- someone else

Q.C12: Is this because of your condition or health problem?

Q. C13: Who helps you with your normal everyday housework such as dusting, tidying up?

- | | |
|-----------------------------|--|
| i) Husband, wife or partner | vi) Other relative |
| ii) Son | vii) Friend or neighbour |
| iii) Daughter | viii) Voluntary organization or agency |
| iv) Parent | ix) Private organization or agency |
| v) Brother or sister | |

Q. C15: Because of your condition, do you need help or ADDITIONAL help doing your normal everyday housework?

Q. C26: Because of your condition, do you receive assistance with personal care, such as washing, grooming, dressing or feeding yourself?

Q. C27: Who helps you with your personal care?

- | | |
|-----------------------------|--|
| i) Husband, wife or partner | vi) Other relative |
| ii) Son | vii) Friend or neighbour |
| iii) Daughter | viii) Voluntary organization or agency |
| iv) Parent | ix) Private organization or agency |
| v) Brother or sister | |

Q. C29: Because of your condition, do you need help or ADDITIONAL help with your personal care?

APPENDIX VII

Questions from the Aboriginal Peoples Survey (Statistics Canada, March, 1994)

Q. C27: Because of your condition or health problem, do you need any help preparing your meals?

Q. C27a.: Are you getting the help you need?

1. Yes - I get all the help I need
2. Yes - sometimes, but I need more help
3. No.

Q. C27b.: Who do you get this help from? Is it from...

1. your spouse, partner, parent, child, or other relative?
2. a friend or neighbour?
3. someone else such as home care service, or privately employed help?

Q. C29: Because of your condition or health problem, do you need any help with your every day housework?

Q. C29a.: Are you getting the help you need?

1. Yes - I get all the help I need
2. Yes - sometimes, but I need more help
3. No.

Q. C29b.: Who do you get this help from? Is it from...

1. your spouse, partner, parent, child, or other relative?
2. a friend or neighbour?
3. someone else such as home care service, or privately employed help?

Q. C32: Because of your condition or health problem, do you need any help with your personal care, such as washing, grooming, dressing and feeding yourself?

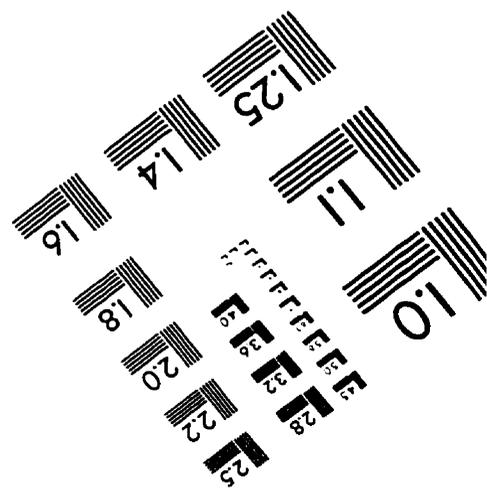
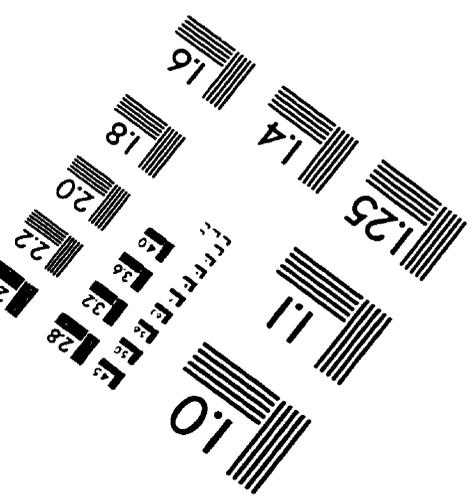
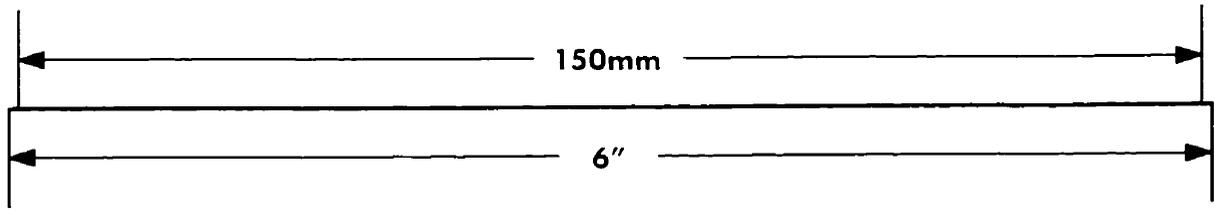
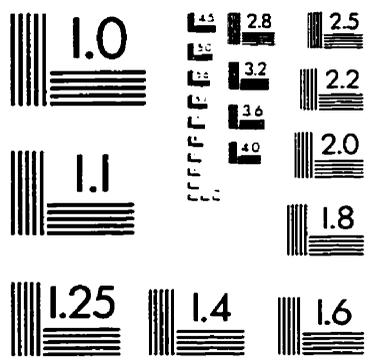
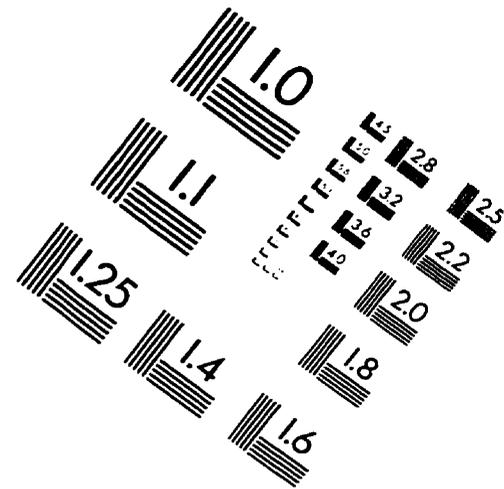
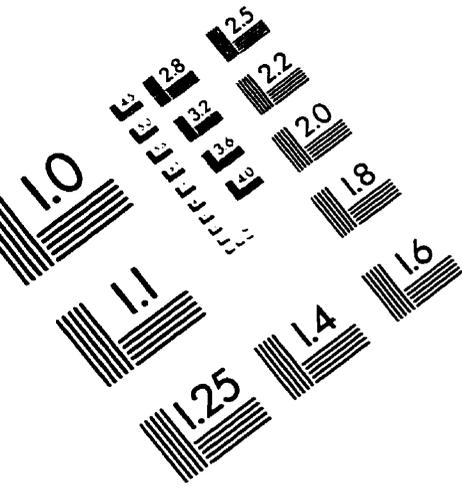
Q. C32a.: Are you getting the help you need?

1. Yes - I get all the help I need
2. Yes - sometimes, but I need more help
3. No.

Q. C32b.: Who do you get this help from? Is it from...

1. your spouse, partner, parent, child, or other relative?
2. a friend or neighbour?
3. someone else such as home care, attendant care, or privately employed help?

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