FIRST NATIONS PEOPLE WITH A DISABILITY NEEDS ASSESSMENT SURVEY FINDINGS[©]

A PROFILE OF MANITOBA FIRST NATIONS PEOPLE WITH A DISABILITY

REPORT PREPARED FOR THE ASSEMBLY OF MANITOBA CHIEFS

BY

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EXECUTIVE SUMMARY

This report was commissioned by the Assembly of Manitoba Chiefs in partnership with the Manitoba First Nation Employment and Training Centres to provide information on Manitoba First Nation peoples with a disability for planning purposes under the Aboriginal Human Resources Development Strategy.

On June 4th 1999, the Assembly of Manitoba Chiefs signed the Aboriginal Human Resources Development Strategy Agreement with the Government of Canada, on behalf of First Nations in Manitoba. The five year labour market initiative assists First Nation communities by providing training and employment opportunities for their constituents. For the first time, persons with a disability were included as one of the designated program areas of the initiative.

Due to the limited dollars allocated to the AHRDS Disability Program, \$333,074 per year, an agreement was made among the First Nation regional training and employment centres and the AMC to use the first year of funding on a needs assessment survey. The AMC in conjunction with the Keewatin First Nations Employment and Training Inc., the Southern Employment and Training Inc., the Winnipeg First Nations Employment and Training Inc., and the First Nations disABILITY Association of Manitoba embarked on a joint process to conduct a needs assessment in all Manitoba First Nation communities.

To undertake such a daunting and costly task, communities were asked to use their funding under this initiative to hire a community member to conduct the needs assessment in their community. Regional coordinators, representing the north and the south, worked with the community surveyors to ensure that the survey activities at the community level were successfully completed. The NHRU was contracted to provide technical expertise and advice on the design of the survey, training of interviewers and data entry people, and analysis of the data.

The working group adopted the following four main objectives to guide the process:

- To identify all First Nation peoples with a disability currently residing in the 63 Manitoba First Nations and to enter their name and address into a registry for future follow-up;
- To determine the socioeconomic factors and job training needs of this group;
- To identify other factors and barriers, such as health, housing, and transportation issues that are related to their disability;
- To provide a final report, complete with recommendations for follow-up and action.

A household "disability screening" questionnaire was developed to screen for all disability types (mobility, agility, visual, mental illness, speech, learning, and developmental disabilities) in adults aged 15 years or older living on reserve. One household member (family member or friend) reported for all household members, including themselves. Community interviewers administered the survey. The survey was divided into two parts. The first section identified the number of adults (aged 15 years or older) and children (under 15 years) with a disability currently living in the household. Additional questions were asked to solicit information on household composition (total number of children, adults under 65, and elders) and to identify all adults (15 years and older) with diabetes. Other questions addressed household socioeconomic conditions such as heating, plumbing facilities, access to transportation, total household income, food security, and working, unemployment, or social assistance status of all adult household members. After all household data was collected and if there were no adults with a disability identified, then the survey was terminated. If an adult (aged 15 years or older) with a disability was identified, the respondent then answered a number of questions on the type of disability, cause of disability, and the number of years living with it. Other questions described the person with a disability's current socioeconomic status, economic insecurity, job training needs, housing barriers, transportation issues, and use of health and social services.

The target population for this survey was all households in the 63 Manitoba First Nation communities. All communities were invited to participate in this study, and 51 communities agreed to participate, with 24 from the north and 27 from the south. Interviewers contacted 7161 households, and 1618 surveys were completed for a First Nation person with a disability.

HIGHLIGHTS

Social Demographics

- The screening survey identified 1618 First Nation adults aged 15 years and older with a disability. It also identified 102 First Nation children with a disability. Interviewers identified more First Nation people with a disability in the north than in the south.
- Overall, equal numbers of men and women with a disability were identified.
 Slightly more women than men were located in the south, but the reasons for this difference are not known at this time.
- Disability is more prevalent in the older age groups. However, a fair number
 of younger First Nation people with a disability were identified. Interviewers in
 the north were able to identify a larger group of older First Nation people with
 a disability.

Health Status

• The average number of years living with a disability was 10 years. However, a large group has lived with a disability for a much longer period of time.

- Although the majority only has one disability, a fair number have two or more disabilities, and the highest reporting of co-disability occurred in the north.
- The most prevalent disability is mobility impairment, followed by agility impairment, legal blindness or visual impairment, and deafness or hard of hearing. A fair number have a mental illness disability, learning disability, speech impairment, or developmental disability.
- Mobility impairment, visual impairment, mental illness, learning disability and speech impairment was slightly higher in the north.
- The major causes of disability were diabetes, accidents or injuries, and birth. Diabetes, in particular, was a major cause of disability in the south. Although the numbers were very small, HIV/AIDS has emerged as a cause of disability in the Manitoba First Nation population, both on and off reserve. The highest single cause of disability was other illnesses, and the north reported the highest proportion.

Socioeconomic Issues

- The households of First Nation people with a disability, particularly in the north, experienced higher forms of socioeconomic disparity in terms of low incomes, high unemployment, and greater dependency on social assistance.
 Food insecurity was a major problem, especially in the north.
- Wages were not the primary source of income for many First Nation people
 with a disability. Social assistance was a major source, followed by old age
 pension. Social assistance was a major source of income in the south, while
 in the north it was old age pension, which is consistent with high number of
 more senior First Nation people with a disability identified in that region.
- Only a small percentage of First Nation people with a disability received income from other benefit plans. A high number were dependent upon income provided by family members, especially in the north. Regardless of region, the vast majority experienced a lack of financial resources in the last six months.
- Like other Manitoba First Nation people, the majority of First Nation people with a disability tend to have only grade nine or less. Only a small number have completed high school and very few have post-secondary training. Education levels were higher in the south than in the north.
- As mentioned, very few First Nation people with a disability are actively
 working. Many work around home. A number of them are involved in
 community activities or are currently volunteering their time. What is
 encouraging is that a fair number continue to participate in traditional
 activities (i.e., hunting, trapping, and fishing). Overall, the data suggests that
 First Nation people with a disability are active, but more so in the south than
 in the north.

Job Training Issues

- Not many First Nation people with a disability have taken a work-related training course. Of those that have received job training, about half of them when attending this training course experienced some difficulties related to their disability.
- For the age group 64 years or younger, the majority of the respondents felt that relocating to another community to receive training would be stressful for a First Nation person with a disability. To make relocating for training a worthwhile experience, a very large number suggested that health or social service support should be provided to a person with a disability.
- Overall, the majority of the respondents felt that information on the Aboriginal Human Resources Development Strategy should be communicated to First Nation people with a disability.

Health Service Issues

- Approximately a third of First Nation people with a disability regularly leave
 their community to see a specialist for their disability or to access specialist
 services in general. Other services utilized include foot care services
 (diabetes related) and physiotherapy or occupational therapy. Very few
 accessed equipment, rehabilitation, mental health, prosthetics or dialysis
 services. What this survey did not identify was the services needed on a
 regular basis, as well as needed but not accessible at this time.
- First Nation people with a disability living in the south tended to use foot care services and services of a physiotherapist or occupational therapist more. Northerners tended to use specialist services in general, specialists for their disability, equipment, and rehabilitation services more often. The reasons as to why they use more technical orientated services are not known at this time. The overall small numbers suggest that there are a few First Nation people with a disability living in communities who have high-level care needs. If these services were more readily available at the community level (e.g. dialysis services), we would perhaps see more high-level care people with a disability who can continue to live in their home community.
- Approximately a half of First Nation people with a disability access escort attendant services for travelling outside the community for medical appointments. Northerners tend to use these services more.
- A good number of First Nations people with a disability depend on homemakers who do light housekeeping, meal preparation, and other related home-related duties. Only a few of them are using personal care attendant services. Again, this survey did not identify the continuing care services that they may require but cannot access, such as the full range of continuing care services available under one jurisdiction like the Manitoba Health continuing care program.
- Overall, many First Nation people with a disability use specialized aids, special dietary food and supplements, or special equipment. Items used most often include special dietary food or supplements and mobility aids (e.g.,

cane, walker or crutches). Other aids utilized include manual wheel chairs, magnifying aids, hearing aids, modified clothing and shoes, and agility aids (artificial limbs, modified eating utensils, writing aids, etc.). Aids, which are more technological or dependent upon services provided by an outside disability agency, were used the least, such as equipment for daily living (bath seats, hospital bed, and bath or chair lifts), power wheel chair, white cane or guide dog, scooter, speaking communication aids or computer speech programs. Again, the survey did not identify need, but access issues was addressed in a limited way. Overall, a good number of First Nation of people with a disability experienced some difficulty in accessing continuing care services, aids, or equipment through Health Canada's Non-Insured Health Benefits Program.

- Community organizations like the health centre, nursing station or Band Office, particularly in the north, were the most supportive of the independent living efforts of First Nation people with a disability.
- The outside organization that supported independent living the most, particularly in the north, was the First Nation Inuit Health Program of Health Canada. Respondents felt that First Nation Tribal Councils and regional organizations were not very supportive, and the institutions identified as doing little to enhance the independent living efforts of First Nation people with a disability were schools, day cares, and personal care homes. In particular, northerners did not feel that outside disability service agencies and Indian Affairs were supportive of the independent living efforts of First Nation people with a disability.

Housing Issues

- First Nation people with a disability were more likely to live in substandard housing, and this disparity was the greatest in northern communities, where the shortage of adequate housing and water and sewage services continue to be a major problem.
- In general, First Nation people with a disability experience a number of physical barriers within their home. What was most striking was the large number of northern First Nation people with a disability that experience physical barriers. The more prevalent barriers were no handrails in bathrooms or on the outside steps. Households did not have an access ramp or ground level entrance. In addition, counter tops were not low enough and doorways or hallways were not wide enough.

Transportation Issues

Approximately a quarter of First Nation people with a disability was not able
to leave their home. A much larger number experienced difficulties making
short trips in their community, and a similar number found it difficult to travel
to nearby communities. By far the greatest travel difficulty cited involved
going on long trips, and northerners tended to experience the greatest
difficulty overall.

- One reason as to why they had difficulty travelling outside their home, particularly within the community, could be due to the unavailability of household transportation. A very large number of First Nation people with a disability reside in homes that do not have access to a motorized vehicle, such as a car, truck, van, boat or snowmobile.
- Other transportation issues exist, such as the provision of accessible and affordable transportation services in communities. Other transportation "barriers" exist such as vehicles that are not physically designed to be accessible to a person with a disability. However, these issues were not examined in this survey.

RECOMMENDATIONS

Policy

- A major cause of disability in First Nation communities is diabetes and diabetes-related complications leading to disability (e.g., visual impairment, circulatory problems, limb loss, and kidney failure). Policy makers, funding agencies, program developers, and health professionals need to urgently address this epidemic. They need to provide preventative measures to minimize complications due to diabetes. They also need to examine ways to improve the quality of life of First Nation people living with a disability due to diabetes-related complications.
- There are many conditions that cause a physical impairment or can restrict the ability of a First Nation person to perform an activity in a manner that is considered normal for a human being. To enhance independent living, services are needed that are specific to the impairment and the disability experienced. Although cases are few at this time, policy makers, program developers and health professionals need to address the needs of First Nation people with a HIV/AIDS related disability.
- The unemployment, poverty, food insecurity, social and geographic isolation, and inadequate living conditions of Manitoba First Nation people with a disability require urgent attention, particularly in the north. Only a small number of First Nation people with a disability receive income from a benefit plan associated with working, such as a disability pension, unemployment insurance, or workers compensation. The vast majority collects social security, depends on income from family members, as well as experiences a lack of financial resources. A social security system for First Nation people with a disability and their families is therefore urgently required. A system is needed to meet the disability-related needs of First Nation people, including families with children with a disability.
- Housing physical barriers need to be addressed. At this time, Canada
 Mortgage and Housing Corporation and Indian Affairs Canada do not address
 the housing needs of First Nation people with a disability. What is required is
 a funding stream that can retrofit exiting homes to encourage the
 independent living efforts of First Nation people with a disability. New building

- codes and policies are also required to accommodate First Nation people with a disability.
- Opportunity and adequate educational resources are needed to meet the
 disability-related needs of First Nation people. Manitoba First Nation people
 with a disability are interested in job training. However, the offering of job
 training should include support services to ensure that training is a worthwhile
 experience, both in the classroom, work place, and the community. Training,
 however, is not enough, and job opportunities have to exist so they can make
 the shift from unpaid work to paid work.
- Overall, all Manitoba First Nations with a disability require accessible healthcare. What is urgently required is a thorough evaluation of Health Canada's Non-Insured Health Benefits Program as it relates to Manitoba First Nation people with a disability. This evaluation should also extend to other federal departments, provincial departments, and provincially funded rehabilitation agencies and programs in terms of the services they offer to First Nation people with a disability, particularly to those First Nation people that live on-reserve.

Research

- Studies are required to understand the social-cultural-economic-andgeographic context of disability in Manitoba First Nation communities.
- Studies are needed to better understand the many types of disabilities or impairments of First Nation people. At question is the type of measures we use to assess disability, functional status, and impairment. New measures, which are more culturally appropriate, are needed to best identify 1) who has a disability, 2) what are the impairments associated with the disability, 3) what are the care related needs associated with the disability and impairment, and 4) what are the barriers experienced as a result of the disability, impairment, and environment in which First Nation people live.
- We know little about the actual delivery of disability-related services to First Nation people with a disability, either on- or off- reserve. We still do not know what actual services are required in the home, the workplace, and the community. We do not have a good grasp of all the transportation barriers that exist, given the isolation of some First Nation communities.
- We need to assess the care that First Nation people with a disability receive from health care professionals and health care institutions to ensure that it is culturally appropriate, respectful, comprehensive, equitable, and reasonably accessible for northern, southern, urban-rural, and urban-Winnipeg First Nation people with a disability.
- Although Canada offers a universal health system, discrimination may be a factor as to why First Nation people have difficulty accessing services, so this area should be studied.
- The experience of families in providing care for and supporting the independent living efforts of First Nation people with a disability need to be understood.

 Of particular interest is the idea that independent living is not just a human rights issue or a constitutional right that First Nation people with a disability share with other people with a disability. Studies are needed to investigate the independent living efforts of First Nation people with a disability as a constituted right of self-government.

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INTRODUCTION

To date, federal and provincial initiatives have not comprehensively addressed the major problems experienced by First Nation people with a disability. The major determinants identified as the cause of their poor health are: 1) jurisdictional problems (federal and provincial governments) in health and social service delivery, 2) unemployment, 3) poverty, 4) social-and-geographic isolation, 5) inadequate living conditions, 6) transportation barriers, and 7) poor access to health services. A number of surveys have reported on the prevalence of disability in the First Nation population, such as the Canadian Health and Activity Limitation Survey (HALS, 1986), Aboriginal People's Survey (1991), Santé Québec Survey (1991), and the First Nations and Inuit Regional Health Survey (1997). All of these surveys, to some degree, identified the continuing care services required by First Nation people with a disability. Little research, however, has investigated the socioeconomic needs of First Nation people with a disability, or the way in which their quality of life could be improved through job training. Currently, programs are being development to ensure that training is available to First Nation people with a disability. Little thought, however, has been given to the health services, social services, and training supports required to make training a worthwhile experience for First Nation people with a disability.

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To undertake such a daunting and costly task, communities were asked to use their funding under this initiative to hire a community member to conduct the needs assessment in their community. Regional coordinators, representing the north and the south, worked with the community surveyors to ensure that the survey activities at the community level were successfully completed. The NHRU was contracted to provide technical expertise and advice on the design of the survey, training of interviewers and data entry people, and analysis of the data.

AMC - AHRDS DISABILITY NEEDS ASSESSMENT SURVEY

The working group adopted the following four main objectives to guide the process:

 To identify all First Nation peoples with a disability currently residing in the 63 Manitoba First Nations and to enter their name and address into a registry for future follow-up;

- To determine the socioeconomic factors and job training needs of this group;
- To identify other factors and barriers, such as health, housing, and transportation issues that are related to their disability;
- To provide a final report, complete with recommendations for follow-up and action.

A household "disability screening" questionnaire was developed to screen for disability in adults aged 15 years or older living on reserve. For this survey, disability was defined as a restriction or lack of ability to live in a manner that is considered normal for a human being as a result of a loss or psychological, physiological, or anatomical structure or functional abnormality (Appendix 2). The survey was designed to identify the many different types of disabilities, which First Nation people can report. The types of disabilities commonly reported are as follows. Mobility impairment is the inability or limited ability to walk, move from room to room, carry an object for 10 meters, or to stand for long periods. Agility impairment is the inability or limited ability to bend, dress or undress oneself, to get in or out of bed, to cut toe nails, to use fingers or hands to grasp or handle objects, or to reach or cut one's own food. Hearing impairment is another disability, where people are either deaf or hard of hearing even with a hearing aid. Visual impairment ranges from being legally blind to being visually impaired even when wearing corrective lens. Speech impairment is the inability or limited ability to speak. Developmental disability involves mental handicap, which limits or prevents the fulfillment of a role that is normal. Learning disability is the difficulty in learning and or remembering due to a brain injury, autism, dyslexia, or FAS/FAE related condition. Mental illness is a disability, particularly due to a long-term emotional, nervous, psychological, or mental health problem or condition. HIV/AIDS related disability is a new emerging disability, which involves a clustering of the many disabilities already mentioned.

The screening survey was designed so that one household member (family member or friend) reported on all household members with a disability. Community interviewers administered the survey. The survey was divided into two parts. The first section identified the number of adults (aged 15 years or older) and children (under 15 years) with a disability currently living in the household. Additional questions were asked to solicit information on household composition (total number of children, adults under 65, and elders) and to identify all adults (15 years and older) with diabetes. Other questions addressed household socioeconomic conditions such as heating, plumbing facilities, access to transportation, total household income, food security, and working, unemployment, or social assistance status of all adult household members. After all household data was collected and if there were no adults with a disability identified then the survey was terminated. If an adult (aged 15 years or older) with a disability was identified, the respondent then answered a number of questions that addressed the type of disability, the cause of the disability, and the number of years living with it. Other questions described the person with a disability's current socioeconomic status, economic insecurity, job training needs, housing barriers, transportation barriers, and use of health and social services.

To minimize the potential for recall bias, community interviewers were instructed to interview the household member who actually has the disability. For this survey, 85% of the respondents reported having a disability and little over half (54%) of this group also answered on behalf of a relative with a disability. In most cases, the household members they answered on behalf of were either their spouse or child. Given that the majority of the respondents provided information on their own disability, reporting bias was minimized in this study.

The target population for this survey was all households in the 63 Manitoba First Nations communities. As of 1999, there was an estimated 13,338 on-reserve households. All First Nation communities were invited to participate. Fifty-one communities agreed to participate, of which 24 were from the north and 27 from the south (Appendix 1).

Recruiting hard to reach populations to participate in a survey, such as people with a disability, is a difficult task at the best of times. Efforts to reach such "hidden" populations are daunting and often challenge methodologists to discover new and creative means for recruitment. Research often has to move outside of traditional study design techniques and into the community at large. Institutional sources such as health centres, for example, only refer people who are in the system, which creates a recruitment bias because this group of participants may be unique. Informal and non-institutional sources of referrals are therefore important as a means of recruiting individuals who are not part of the system, either out of choice or because they have not been able to get access.

For this study, it was agreed that contacting all households would be difficult because the resources needed to achieve this goal were not adequate, especially in the larger communities. Participating communities had enough resources to hire one interviewer. In the small communities, one interviewer was sufficient to conduct the survey, but two or three interviewers were required in the larger communities. To contact as many First Nations people with a disability as possible, a number of strategies were developed.

Interviewers were instructed to go from house to house, where possible, to screen for First Nation people with a disability. In larger communities, interviewers used health centre chronic disease registries to identify community members with a disability. Interviewers also used a snowball approach and asked family members, friends, or the

people they already interviewed to identify other households where a First Nation person with a disability may reside. Interviewers from the smaller communities also assisted with data collection efforts in larger nearby communities. In some communities, the Band Office provided additional resources to hire another interviewer.

By using this combined approach, interviewers contacted 7161 households. They identified 1676 households where a First Nation person with a disability resided (Table 1). Significantly, more households were contacted in the north than in the south. The total number of completed surveys for a person with a disability was 1618. Fifty-eight surveys were not filled in for a First Nation person identified with a disability. The failure to complete these surveys occurred in households of more than two adults with a disability. In these households, the respondents may not have provided information on all adult household members identified with a disability, or the interviewer may have inadvertently failed to collect this information.

Table 1: Number of households contacted by region and disability.

HOUSEHOLDS CONTACTED	REGIONAL	North	South
TOTAL NUMBER OF HOUSEHOLDS CONTACTED	6980/11,227 = 62%	4378/5822 = 75%	2602/5405 = 48%
Households with no adults with a Disability	5508	3557	1951
Households with one adult with a disability	1281	692	589
Households with two adults with a disability	173	118	56
Households with three or more adults with a disability	18	11	6

LIMITATIONS OF THE STUDY

A major limitation of this study was that we were not able to thoroughly evaluate the reliability and validity of the measures used in the survey instrument. The instrument was pretested, but more work could have been done to ensure that the measures used had accurately reflected the social and cultural context of First Nation people with a disability. Given that this was not done, construct validity may be an issue. A greater investment of time and research dollars is therefore needed to develop measures that adequately reflect the realities of First Nation people with a disability.

Proxy interviews can also be problematic, particularly for recall bias. The bias in this study is not fully known. We did not assess the level of agreement between the answers provided by proxy respondents and the answers provided by the family member they answered on behalf of. In proxy surveys, there is generally excellent agreement for explicitly defined and distinct conditions, as well as functional needs and barriers. Specific questions were asked where possible. However, more specific questions could have been asked but were outside of the scope of this study.

RESULTS

DISABILITY AND RELATED CAUSES

The screening survey was able to identify 1618 First Nation adults aged 15 years and older with a disability and 102 First Nation children with a disability. Interviewers located more First Nation adults with a disability in the north (58%) than in the south (42%) (Figure 1). Overall, equal numbers of First Nation women and men with a disability were identified. However, interviewers working in the southern communities located more First Nation

women with a disability (54%) than men (46%) (Figure 2). Reasons for this difference are not clear. How the survey was conducted in the community could have biased the results. On the other hand, differences could be a characteristic of the communities that participated, or could be that more First Nation women in the south have a disability than do men.

Consistent with our understanding of disability, it is more prevalent in the older age groups. The average age of a First Nation person with a disability was 52 years of age. Nearly 70% of First Nation people with a disability were 45 years or older (Figure 3). The screening survey also identified a number of younger people with a disability. Approximately 10% of adult First Nation people (15 years or older) with a disability were under 24 years of age, and 25% were between the ages of 25 to 44 years. The age distribution varied by region. In the south, more First Nation people with a disability were identified in the age groups 25 to 64 years. In the north, interviewers located more First Nation people with a disability aged 65 years or older.

Figure 1: Regional Variations

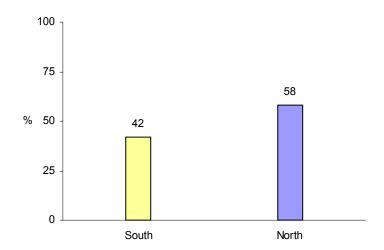


Figure 2: Variations by gender and region

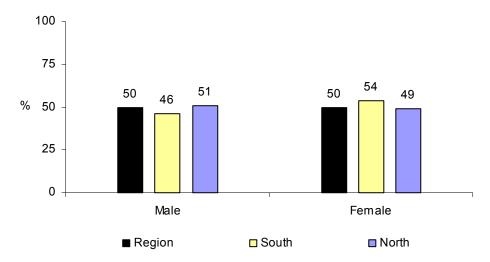
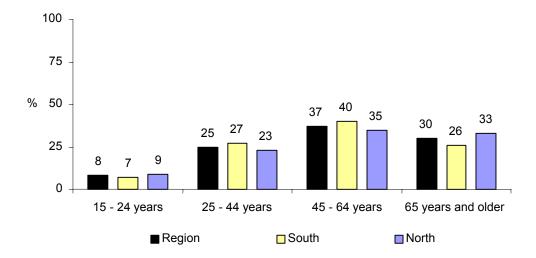


Figure 3: Variations by age and region



The median number of years living with a disability, regardless of region, was 10 years. Fifty-six percent of First Nation people with a disability have had a disability for less than 10 years (Figure 4). A similar sized group (46%), however, has lived with it for a much longer period of time. Overall, a majority (74%) has one disability, while 24% have two or more disabilities (Figure 5). The highest reporting of co-disability occurred in the north (28%).

Figure 4: Total number of years living with a disability by region

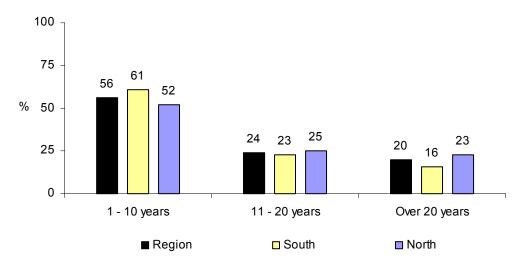
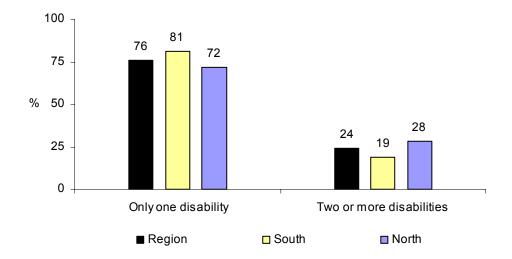
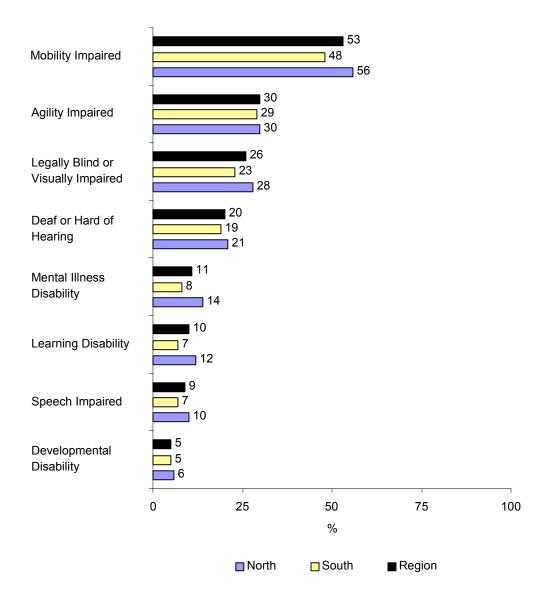


Figure 5: Reports of single or multiple disabilities by region



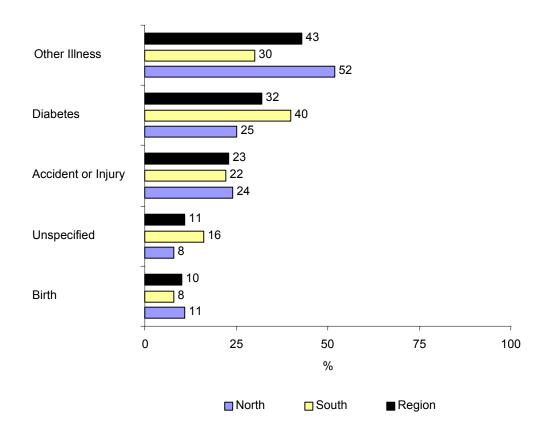
The most prevalent form of disability was mobility impairment (43%), followed by agility impairment (30%), legal blindness or visual impairment (26%), and deafness or hard of hearing (20%) (Figure 6). Other disabilities included mental illness (11%), learning disability (10%), speech impairment (9%), and developmental disabilities (5%). Regional variation was evident in that mobility impairment, visual impairment, mental illness, learning disability, and speech impairment were slightly higher in the north.

Figure 6: Types of disability by region



The major causes of disability included diabetes (32%), accidents or injuries (23%), and birth (10%) (Figure 7). Diabetes, in particular, was a major cause of disability in the south (40%). Although the numbers were small, it is important to note that HIV/AIDS has emerged as a cause of disability in the Manitoba First Nation population, both on- and off-reserve. The highest single cause of disability was other illnesses (54%) not identified, and these unidentified causes were more prevalent in the north than in the south.

Figure 7: Cause associated with disability by region



SOCIOECONOMIC ISSUES

In households that reported no household members with a disability, there were more adults working, incomes were higher, and the experience of food insecurity was much less. The opposite was true for households where at least one adult member had a disability. In these households, a large number of respondents (60%) reported a total household income of below 20,000 dollars (Figure 8). As well, fewer adults were working (40%), and more adults were on social assistance (71%) (Figure 9). A little over half (51%) also indicated that, in the last six months, their household ran out of money for food (Figure 10). This disparity was even greater in the north, where the households of First Nation with a disability tended to have less income and were more likely to experience food insecurity.

Figure 8: Total household income reported in households of First Nation people with a disability

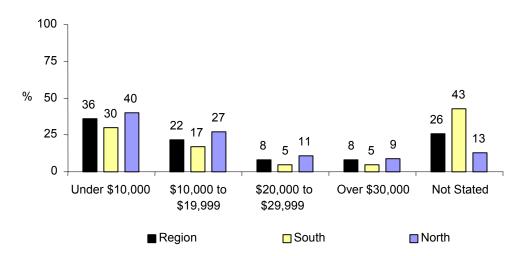


Figure 9: Economic characteristics reported on adults in households of First Nation people with a disability by region

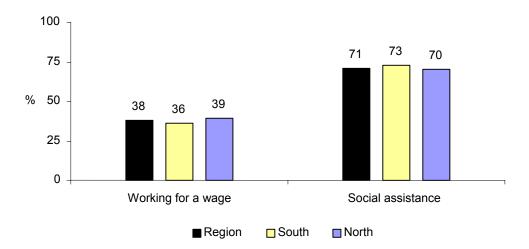
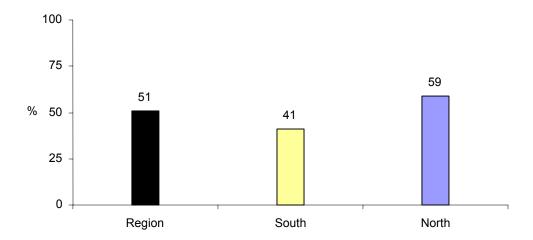


Figure 10: Experience of food insecurity (running out of money for food) in households of First Nation people with a disability by region



Such high disparity was also experienced at the individual level. Only 20% of First Nation people with a disability obtained their income from wages (Figure 11). A large number (53%) depended upon social assistance as a major source of income. Another major source of income was old age pension (35%). A small percentage (15%) received income from another benefit plan (15%) (disability pension, unemployment insurance, motor vehicle insurance, and workers compensation), and a similar number (15%) relied on income from other sources. Another major finding was that a large number of First Nation people with a disability (61%), regardless of their source of income, relied on income provided by family members (Figure 12). Given these circumstances, nearly 70% of First Nation people with a disability experienced a lack of financial resources in the last six months (Figure 13). Regional differences were apparent. In the south, a large of First Nation people with a disability relied on social assistance (58%). In the north, the major source of income was old age pension (39%). First Nation people with a disability from the north were also more dependent on income provided by family members (67%)



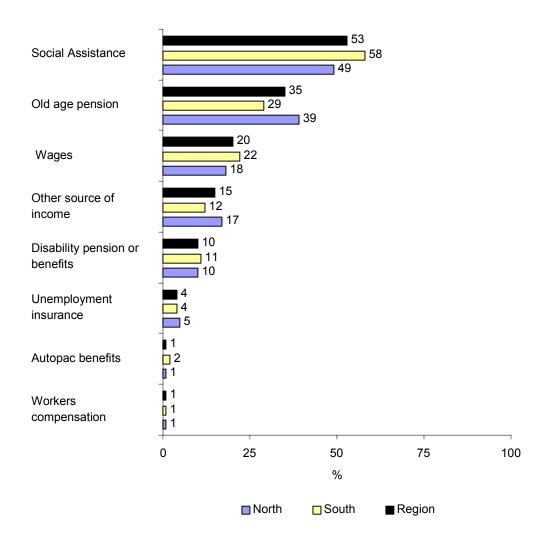


Figure 12: Proportion of First Nation people with a disability who are dependent on the income provided by family members by region

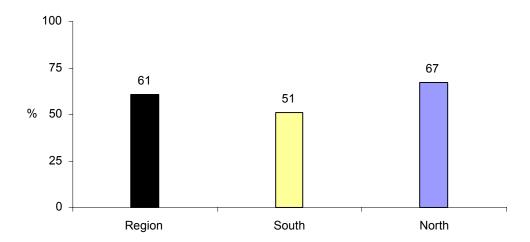
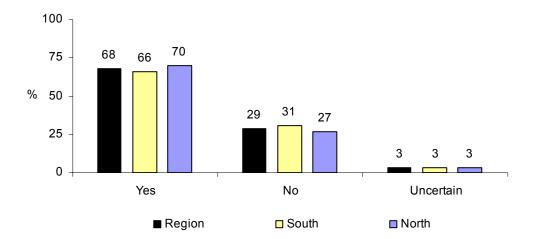


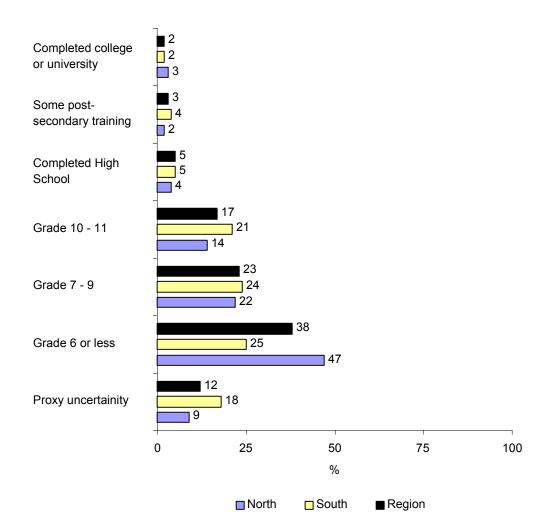
Figure 13: Proportion of First Nation people with a disability who experienced a lack of financial resources in the last six months by region



The educational profile of First Nation people with a disability was fairly consistent with the educational levels achieved by Manitoba First Nation peoples living on reserve, as reported by the Manitoba First Nation Regional Health Survey. Most First Nation people with a disability (61%) have only achieved grade nine or less (Figure 14). Only 17% completed high school and a much small number (5%) received some post-secondary education. Higher levels of education tended to be achieved in the south, while the opposite was true in

the north where 46% of First Nation people with a disability only attained a lesser level of education.

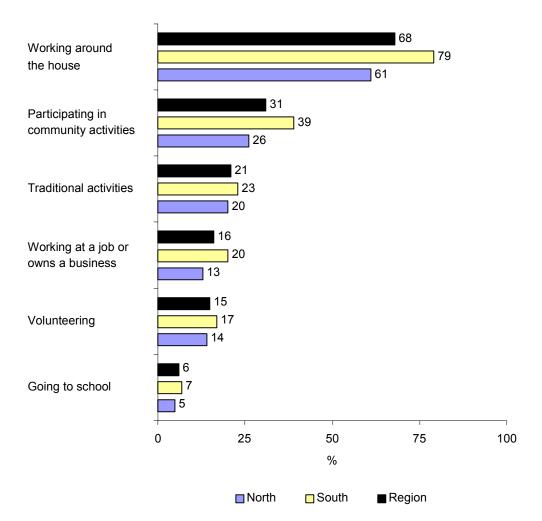
Figure 14: Highest level of education achieved by First Nation people with a disability by region



Overall, only 16% of First Nation people with a disability were working at a job or owned their own business (Figure 15). A small number (6%) were currently attending school. The activity most performed (68%) by this group was working around the home. Approximately a third (31%) were involved in community activities, and about 15% actually volunteered their time. What was most encouraging was that 21% still participated in

traditional activities (e.g., hunting, fishing and trapping). In terms of regional differences, southern First Nation people with a disability were, by and large, the most active.

Figure 15: Everyday activities of First Nation people with a disability by region



JOB TRAINING ISSUES

The survey found that some First Nation people with a disability (20%) have taken a work-related training course (Figure 16), and during this training, about half of them experienced some difficulties related to their disability. For the cohort under 65 years of age, the majority (60%) of the respondents felt that moving to another community to receive work

related training would be particularly stressful for the individual in question (Figure 17). To make relocating for training a worthwhile experience, nearly three quarters (72%) suggested that support (e.g. continuing care services, transportation, and housing) from health or social service agencies would be required, including aids and devices to assist and enhance their training or employment experience (Figure 18).

Figure 16: Job training history and difficulties experienced by First Nation people with a disability by region

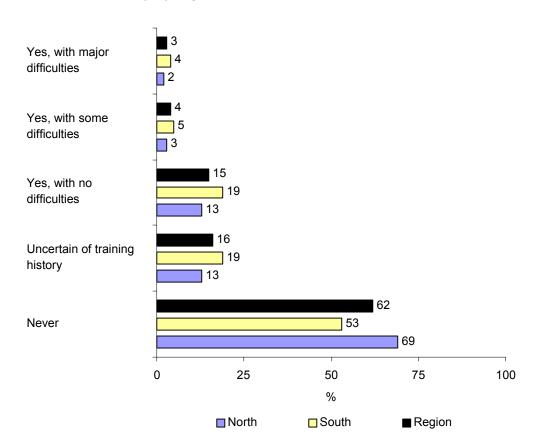


Figure 17: Proportion of respondents who felt that relocating to another community for job training would be stressful for First Nation people with a disability who are less than 65 years of age, by region

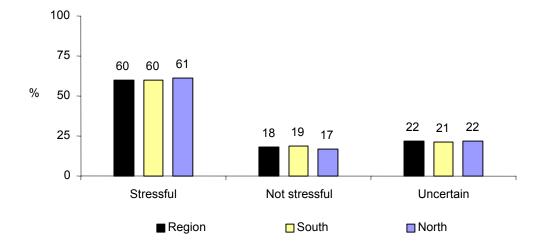
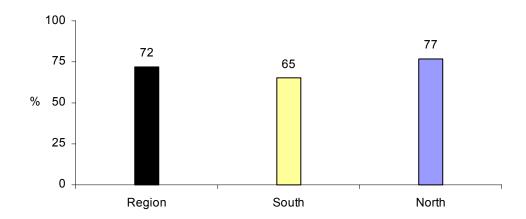
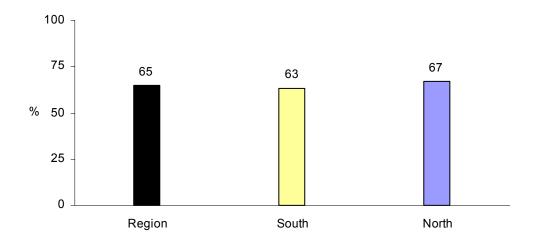


Figure 18: Proportion of First Nation people with a disability under 65 years of age who would require support to enhance their job training experience, by region



Although training barriers exist for this group, the majority of the respondents (65%) felt that First Nation people with a disability would still be interested in receiving more information about the Aboriginal Human Resources Development Strategy (Figure 19).

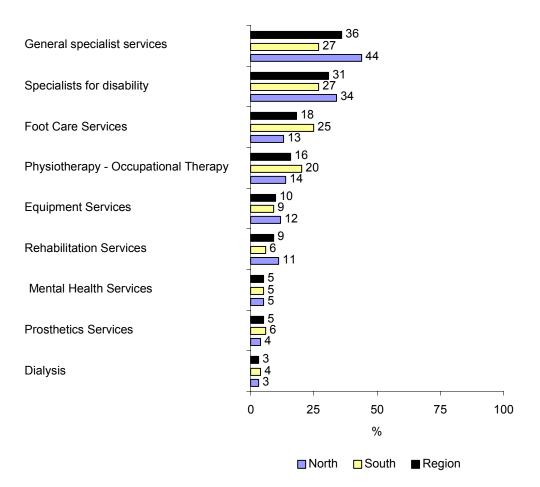
Figure 19: Proportion of First Nation people with disabilities under 65 years who would like to know more about the Aboriginal Human Resources Development Strategy, by region



HEALTH SERVICE ISSUES

Approximately a third of First Nation people with a disability regularly left their community to see a specialist for their disability or to access specialist services in general (Figure 20). Other services used on a regular basis included foot care services (diabetes related) (31%) and services provided by a physiotherapist or occupational therapist (16%). Equipment (10%), rehabilitation (9%), mental health (5%), prosthetics (5%), and dialysis services (3%) were also utilized, but not in great numbers. In the north, First Nation people with a disability tended to use specialist services in general (44%), specialists for their disability (34%), and equipment (12%) or rehabilitation services (11%) more. The southern group was more likely to use foot care services (25%) or services of a physiotherapist or occupational therapist (20%).

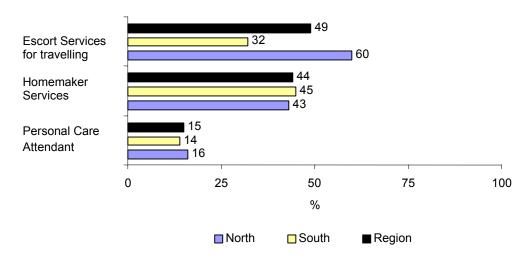
Figure 20: Proportion of First Nation peoples with a disability who regularly obtain health services from outside their community, by region



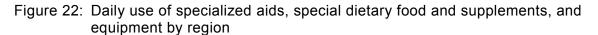
A large number of First Nations people with a disability also use a range of continuing care services. A majority (49%) regularly use the escort service program provided through Health Canada's Non-Insured Benefits Program for travelling outside the community for medical appointments (Figure 21). A good number (44%) also rely on homemakers for light housekeeping, meal preparation, or other household services like cutting wood or washing clothes. A few of them (15%) also need someone to take care of their personal needs (e.g., dressing, washing, etc.). In terms of regional variation, the reliance on escort attendants for travelling was much higher in the north (60%), which may be due to greater

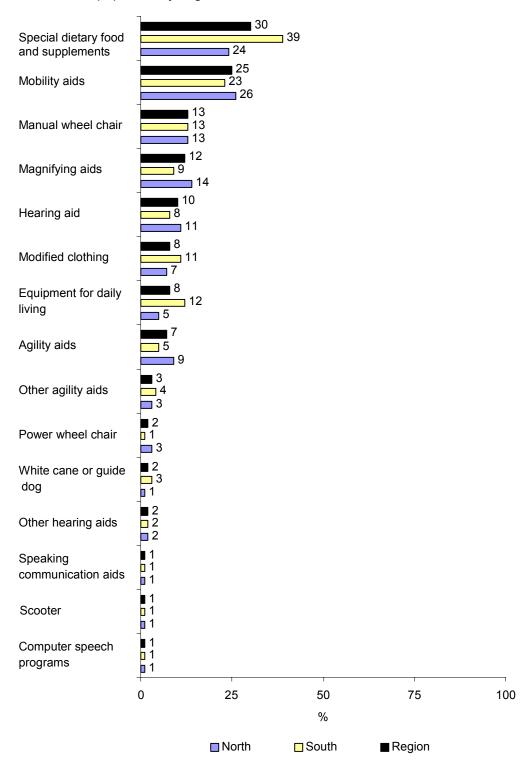
isolation and distances traveled. It should be noted, however, that a good number of First Nation people with a disability (32%) from the south also used these services.

Figure 21: Use of continuing care services by First Nation people with a disability by region



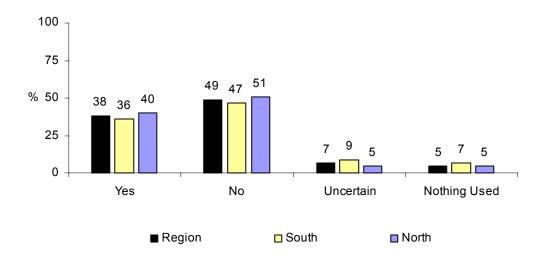
Health Canada's Non-Insured Health Benefits Program provides a variety of specialized aids, food supplements, or special equipment to First Nation people with a disability. According to this survey, the items most often used on a daily basis (Figure 22) were special dietary food and supplements (30%) and mobility aids (e.g. canes, walkers, and crutches) (25%). Other aids utilized were manual wheel chairs (13%), magnifying aids (12%), hearing aids (10%), modified clothing (8%), and equipment for daily living such as special lifts or beds (8%). The aids accessed the least were agility aids (from artificial limbs to modified eating utensils), power wheel chairs or scooters, white cane or guide dog, or various types of communication aids (bliss board for speaking or speech programs for the visually impaired). In other words, aids, which are more technological or dependent upon services provided by an outside disability agency or equipment supplier, were used the least.





First Nation people with a disability are reliant on a number of continuing care services, aids, and equipment provided by the Non-Insured Health Benefits Program. These services, however, have not always been accessible, and this survey has revealed that a significant number (40%) of First Nation people with a disability have experienced some difficulty obtaining these services or aids for their disability (Figure 23).

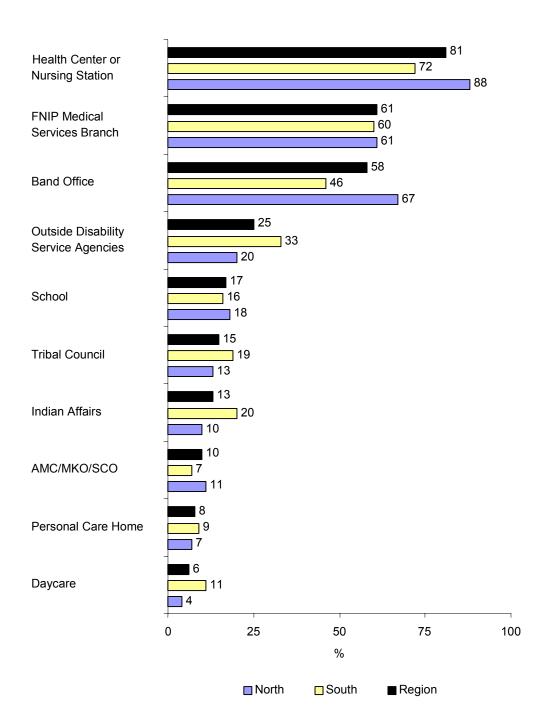
Figure 23: Proportion of First Nation people with a disability who had difficulty obtaining specialized aids, dietary supplements, or equipment from the Health Canada's Non-Insured Health Benefits Program by region



Overall, the survey has illustrated that First Nation people with a disability require some level of support to enhance their independence either at home, in the community, or when they travel. In the community, the organizations that supported independent living the most was the health center or nursing station (81%), followed by the band office (58%) (Figure 24). Northerners particularly found these organizations to be the most helpful (88% and 67% respectively). Respondents viewed community schools (17%) and day cares (6%) as not as supportive, and the same was true for personal care homes (8%). The most supportive organization outside the community was the Health Canada's First Nation and Inuit Health Program. Very few respondents identified tribal councils (15%), or other regional

First Nation organizations (8%) like the Assembly of Manitoba Chiefs, Manitoba Keewatinowi Okimakanak, or the Southern Chiefs Organization as particularly helpful. Respondents also did not feel that outside disability service agencies and regional governments like Indian Affairs were promoting, supporting, or maintaining the independent living efforts of First Nation people with a disability, particularly in the north.

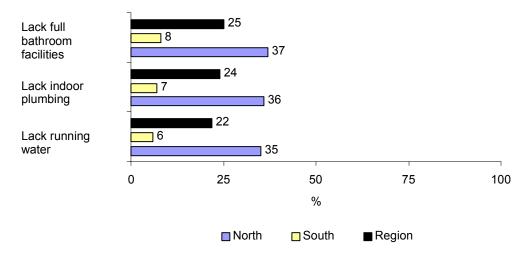
Figure 24: Respondent's perception of the helpfulness of agencies in supporting the independent living efforts of First Nation peoples with a disability by region



HOUSING ISSUES

Obtaining adequate housing is a major problem for most, if not all, Manitoba First Nation people. Approximately 17% of all respondents participating in the screening survey did not have running water or adequate plumbing facilities in their home. This disparity was much higher in households where a First Nation person with a disability resided (25%), and was significantly higher (37%) in northern communities (Figure 25). Although the vast majority of households in the south had adequate facilities, a number of them (approximately 7%) still lacked this basic necessity.

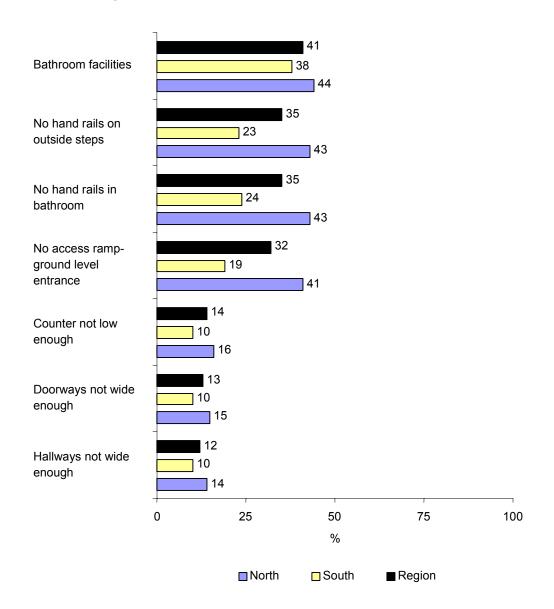
Figure 25: Proportion of First Nation people with a disability who live in households that lack plumbing facilities by region



Adequate bathroom facilities (ranging from 35 to 40%) was just one of many physical barriers that First Nation people with a disability must face in their homes (Figure 26). Other physical barriers encountered included no handrails on the outside steps (35%) and no access ramp or ground-level entrance (32%). Other barriers experienced were counters that were not low enough (14%) or doorways (13%) or hallways (12%) that were not wide

enough. In terms of regional variations, accessible bathrooms and entranceways were the most problematic in the north.

Figure 26: Physical barriers in households of First Nation people with a disability by region



TRANSPORTATION ISSUES

A number of First Nation people with a disability experienced some difficulty leaving home or travelling as a result of their disability. Approximately a quarter was not able to

leave their home. A larger number (28%) experienced difficulties travelling around their own community. A similar number found it difficult to travel to nearby communities, and nearly 40% experienced difficulties when they went on long trips. Northerners tended to experience the greatest difficult overall (Figure 27). Accessible transportation was one reason as to why they had difficulty getting around. For one, a very large number of First Nation people with a disability reside in homes that do not have access to a motorized vehicle, such as a car, truck, van, boat, or snowmobile (Figure 28).

Figure 27: Proportion of First Nation people with a disability who experience difficulty leaving home or travelling by region

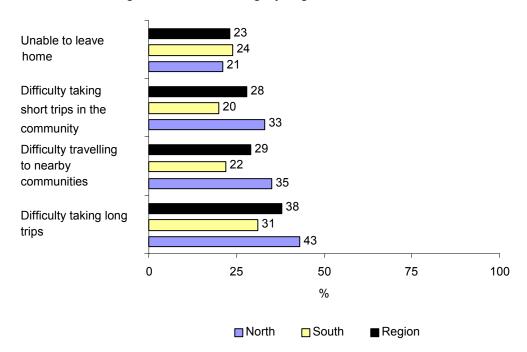
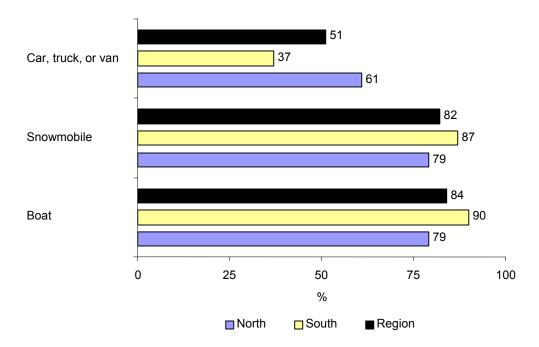


Figure 28: Households of First Nation people with a disability that do not have access to transportation by region



CONCLUSION

This screening survey identified 1618 First Nation adults aged 15 years and older with a disability. It also identified 102 First Nation children with a disability. Interviewers located more First Nation people with a disability in the north (58%) than in the south (42%). Overall, equal numbers of First Nation women and men with a disability were identified. However, slightly more First Nation women (54%) with a disability were located in the south than were men (46%). Disability was more prevalent in the older age groups (67%). As for regional differences, southern interviewers located more First Nation people with a disability in the age groups 25 to 64 years, while interviewers in the north located a much older group.

The types of disability are varied and complex. The average number of years living with a disability was 10 years. However, a large group has lived with a disability for a long

period of time. Although the majority only has one disability, many have two or more disabilities, and the highest reporting of co-disability occurred in the north. The most prevalent disability is mobility impairment, followed by agility, legal blindness or visual impairment, and deafness or hard of hearing. A fair number have a mental illness disability, learning disability, speech impairment, or developmental disability. Mobility impairment, visual impairment, mental illness, learning disability and speech impairment was slightly higher in the north. Overall, the highest single cause of disability was other illnesses, and the north reported the highest proportion. Specific causes of disability were diabetes, accidents or injuries, and birth. Diabetes, in particular, was a major cause of disability in the south. Although the numbers were very small, HIV/AIDS has emerged as a cause of disability in the Manitoba First Nation population, both on and off reserve.

The households of First Nation people with a disability, particularly in the north, experienced higher forms of socioeconomic disparity in terms of low incomes, high unemployment, and greater dependency on social assistance. Food insecurity was a major problem, especially in the north. Not many First Nation people with a disability work. Social assistance was a major source of income in the south. In the north, it was old age pension. Only a small percentage of First Nation people with a disability received income from other benefit plans. A high number were dependent upon income provided by family members, especially in the north. Regardless of region, a very large number of First Nation people with a disability experienced a lack of financial resources in the last six months.

Like other Manitoba First Nation people, the majority of First Nation people with a disability tend to have only grade nine or less. Not many have completed high school and very few have received post-secondary education. Education levels seem to be higher in the south than in the north. As mentioned, only a few First Nation people with a disability work.

A majority tends to work around home, and approximately a third were involved in community activities, and some have volunteered their time. What was most encouraging was that a fair number continue to participate in traditional activities (i.e., hunting, trapping, and fishing). Overall, First Nation people with a disability are active, and they are more active in the south than in the north.

Not many First Nation people with a disability have taken a work-related training course. About half of this group experienced some difficulties at these training courses due to their disability. For the age group 64 years or younger, the majority of the respondents felt that relocating to another community to receive training would be stressful for a First Nation person with a disability. To make relocating for training a worthwhile experience, the majority suggested that health or social service support should be provided to a person with a disability. Overall, a large number of respondents felt that information on the Aboriginal Human Resources Development Strategy should be communicated to First Nation people with a disability.

A fair number of First Nation people with a disability regularly leave their community to see a specialist for their disability or to access specialist services in general. Other services utilized include foot care services (diabetes related) and physiotherapy or occupational therapy. Very few access equipment, rehabilitation, mental health, prosthetics, or dialysis services. What this survey did not identify was the services needed on a regular basis, but not accessed at this time. First Nation people with a disability living in the south tend to use foot care services and services of a physiotherapist or occupational therapist more, while northerners use specialist services in general, specialists for their disability, equipment, and rehabilitation services. The reasons as to why northerners use more technical orientated services are not known at this time. The small numbers overall suggest

that there are a few First Nation people with a disability who have high level care needs living in First Nation communities. If these services were more readily available in the community (e.g. dialysis services), we would perhaps see more high-level care people with a disability living in their communities.

Approximately a half of First Nation people with a disability access escort attendant services for travelling outside the community for medical appointments. Northerners tend to use these services more. A good number tended to rely on homemakers who do light housekeeping, meal preparation, and other home related duties. Only a few of First Nation people with a disability use personal care attendant services. Again, this survey did not identify the continuing care services that are required but not accessed such as the full range of continuing care services offered by the Manitoba Health continuing care program.

Overall, many First Nation people with a disability use specialized aids, special dietary food and supplements, or special equipment. Items used most often include special dietary food or supplements and mobility aids (e.g., cane, walker or crutches). Other aids utilized include manual wheel chairs, magnifying aids, hearing aids, modified clothing and shoes, and agility aids (artificial limbs, modified eating utensils, writing aids, etc.). Aids, which are more technological or dependent upon services provided by an outside disability agency, were used the least, such as equipment for daily living (bath seats, hospital bed, and bath or chair lifts), power wheel chair, white cane or guide dog, scooter, speaking communication aids or computer speech programs. Again, the survey did not identify need, but access issues were addressed in a limited way. Overall, a large number of First Nation of people with a disability experienced some difficulty in accessing continuing care services, aids, or equipment through Health Canada's Non-Insured Health Benefits Program.

Another finding of this survey was that respondents felt that community-based organizations like the health centre, nursing station, or Band Office were the most supportive of the independent living efforts of First Nation people with a disability, particularly in the north. The outside organization they identified as the most supportive of independent living, especially in the north, was Health Canada's First Nation Inuit Health Program. Respondents felt that First Nation Tribal Councils and regional organizations were not very supportive, and the institutions identified as doing little to enhance the independent living efforts of First Nation people with a disability were schools, day cares, and personal care homes. Northerners, in particular, did not feel that outside disability service agencies and Indian Affairs were supportive of the independent living efforts of First Nation people with a disability.

In terms of housing, First Nation people with a disability were more likely to live in substandard housing, and this disparity was the greatest in the north, where the shortage of adequate housing and water and sewage services continue to be a major problem. First Nation people with a disability also experience a number of physical barriers within their home. What was not surprising was the large number of northern First Nation people with a disability that experienced physical barriers. The more prevalent barriers cited were no handrails in bathrooms or on the outside steps. Households also did not have an access ramp or ground level entrance. In addition, counter tops were not low enough and doorways or hallways were not wide enough.

Approximately a quarter of First Nation people with a disability was not able to leave their home. A much larger number experienced difficulties making short trips in their community, and a similar number found it difficult to travel to nearby communities. By far the greatest travel difficulty cited involved going on long trips, and northerners tended to

experience the greatest difficulty overall. A lack of accessible transportation at the household level was a major barrier. A very large number of First Nation people with a disability reside in homes that do not have access to a motorized vehicle, such as a car, truck, van, boat or snowmobile. Other accessible transportation issues exist, such as the provision of accessible and affordable transportation services (taxis, handicap transit, etc.) in the communities. However, they were not examined in this survey.

In summary, this report illustrates that federal, provincial, First Nation initiatives are required to address major problems experienced by First Nation people with a disability. Inadequate programs will only but continue to create frustration for First Nation people with a disability, as well as for family members who provide a significant amount of support to family members who have a disability. The following is a number of policy and program areas that need to be addressed.

RECOMMENDATIONS

The policy and programs areas that require urgent attention are as follows:

- The Manitoba First Nation people with a disability registry project should be fully supported so the Assembly of Manitoba Chiefs can provide information to First Nation people with a disability and their families on the health, social, housing, transportation, economic, education, and advocacy services available to them.
- 2. A range of causes has been associated with disability in Manitoba First Nation communities. A major cause is diabetes and diabetes-related complications leading to a disability (e.g., visual impairment, circulatory problems, limb loss, and kidney failure). Policy makers, funding agencies, program developers, and health professionals need to urgently address this epidemic. They need to

- provide preventative measures to minimize diabetes- related complications. They also need to examine ways to improve the quality of life of First Nation people who have a disability due to a diabetes- related complication.
- 3. There are many conditions that cause a physical impairment and that can restrict the ability of a First Nation person to perform an activity in a manner that is considered normal for a human being. To enhance independent living, services are urgently needed which are specific to the impairment and the disability experienced. Although cases may be few at this time, policy makers, program developers and health professionals need to address the needs of First Nation people with a HIV/AIDS related disability.
- 4. The unemployment, poverty, food insecurity, social and geographic isolation, and inadequate living conditions of Manitoba First Nation peoples with a disability require urgent attention, particularly in the north. Only a small number receive income from a benefit plan related to working, such as a disability pension, unemployment insurance, or workers compensation. First Nation people with a disability need to work in order to be eligible to receive such benefits. At this time very few are working. A social security system is needed to meet the disability-related needs of First Nation people with a disability, including families with children with a disability.
- 5. Housing physical barriers need to be addressed. At this time, Canada Mortgage and Housing Corporation and Indian Affairs Canada do not address the housing needs of First Nation people with a disability. To encourage, support, and maintain independent living, what is required is ongoing funding to retrofit exiting and future homes of First Nation people with a disability. New building codes and

policies are also required to further accommodate First Nation people with a disability.

- 6. Opportunity and adequate educational resources are needed to meet the disability-related needs of First Nation people. Manitoba First Nation people with a disability are interested in job training. However, the offering of job training should include support services to ensure that training is a worthwhile experience, both in the classroom, work place, and the community. Training, however, is not enough, and job opportunities have to exist so they can make the shift from unpaid work to paid work.
- 7. Overall, all Manitoba First Nations with a disability require accessible healthcare. What is urgently required is a thorough evaluation of Health Canada's Non-Insured Health Benefits Program as it relates to Manitoba First Nation people with a disability. This evaluation should also extend to other federal departments, provincial departments, and provincially funded rehabilitation agencies and programs in terms of the services they offer to First Nation people with a disability, particularly to those First Nation people that live on-reserve.

To monitor these develops and to broaden our understanding of disability in First Nation communities, the following research projects should be undertaken:

- The Manitoba First Nation people with a disability registry project should be maintained to provide the means to access First Nation people with a disability to get their feedback on the nature of their disability, impairment, functional needs, and health and social service experiences.
- Studies are required to understand the social-cultural-economic-and-geographic context of disability in Manitoba First Nation communities.

- 3. At this time, we do not have a full understanding of the many types of disabilities or impairments of First Nation people. At question is the type of measures we use to assess disability, functional status, and impairment. New measures, which are more culturally appropriate, are needed to best identify 1) who has a disability, 2) what are the impairments associated with the disability, 3) what are the care related needs associated with the disability and impairment, and 4) what are the barriers experienced as a result of the disability, impairment, and environment in which First Nation people live.
- 4. We also know very little about the actual delivery of disability-related services to First Nation people with a disability, either on- or off- reserve. More research is required to understand what, where, when, why and how services are provided in the home, the workplace, and the community. We also need to know what services are needed, but not provided. We also do not have a good grasp of all the transportation barriers that exist for First Nation people with a disability.
- 5. We also need to evaluate the care that First Nation people with a disability receive from health care professionals and health care institutions to ensure that it is culturally appropriate, respectful, comprehensive, equitable, and reasonably accessible to northern, southern, urban-rural and urban-Winnipeg First Nation people with a disability.
- Although Canada offers a universal health system, discrimination may be a factor
 as to why First Nation people with a disability have difficulty accessing services,
 so this area should be studied.
- 7. The experience of families in providing care for and supporting the independent living efforts of First Nation people with a disability need to be understood to ensure adequate supports are in place for families.

8. Of particular interest is the idea that independent living is not just a human rights issue or a constitutional right that First Nation people with a disability share with other people with a disability. Studies are needed to investigate the independent living efforts of First Nation people with a disability as a constituted right of self-government.

APPENDIX 1

AMC - AHRDS NEEDS ASSESSMENT WORKING GROUP

STAN BEAR ASSEMBLY OF MANITOBA CHIEFS (AMC) - AHRDS

DOREEN DEMAS ADVISOR ON DISABILITY ISSUES - AMC

KAREN HARPER ADMINISTRATIVE ASSISTANT – AMC

LINDA FORTIN AHRDS NORTHERN CO-ORDINATOR

DIANE SCRIBE AHRDS SOUTHERN CO-ORDINATOR/FIRST NATIONS DISABILITY

ASSOCIATION OF MANITOBA INC.

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NORTH - PARTICIPATING COMMUNITIES AND SURVEYORS

COMMUNITY

SURVEYOR

Barren Lands (Brochet)
Chemawawin
Colin George
Pimicikamak (Cross Lake)
Fox Lake
Garden Hill
God's Lake
Marcel Colomb
Darlene Clark
Colin George
Merle Scatch
Jessie Anderson
Leonard Wood
Deborah Mason
Crystal Michelle

Mathias Colomb (Pukatawagen) Mindy Bear / Moses Castel

Mosakahiken Cree (Moose Lake) Elias Martin Nisichawayasihk Cree (Nelson House) **Howard Hunter** Northlands (Lac Brochet) Lizzette Denechezhe Norway House George Duncan Opaskwayak Cree (OCN) John Paul Martin Oxford House Louise Munroe Red Sucker Lake Elma Harper Sapotaweyak (Shoal River) Shelley Genaille Sayisi Dene (Tadoule Lake) Clayton Cheekie Shamattawa Liberty Redhead South Indian Lake Irene Soulier St. Theresa Point Elia Taylor War Lake Isabel Ouskan

Wuskwi Sipihk Lucy Audy York Factory Obediah Wastesicoot

SOUTH - PARTICIPATING COMMUNITIES AND SURVEYORS

COMMUNITY

SURVEYOR

Berens River
Birdtail Sioux
Bloodvein
Brokenhead
Burdtail Sioux
Brokenhead
Brokenhead
Burdtail Sioux
Brokenhead
Brokenhead
Brokenhead
Burdtail Sioux
Burdtai

Canupawakpa (Oak Lake) Tara Wasicurna/Victorine Royale

Dakota Plains Octavia tabaracci-Chaske

Ebb & Flow
Fairford
Fairford
Fisher River
Gamblers
Kinonjeoshtegon (Jackhead)
Lake St. Martin
Little Black River

Delores Houle
Tammy Woodhouse
Rachel Murdock
Derek Tanner
Charlene Oigg
George Sinclair
Crystal Bird

Long Plains Gerald Thunderbird-Sky

Paungassi Leon Green Peguis Aldona Stevenson Pine Creek Calvin Nepinak Valerie Davis Polar River Rolling River Myma Young Roseau River Gloria Littlejohn Arnold Spence Sandy Bay Sioux Valley Joanne McKay Swan Lake Eric Cameron Waterhen **Nelson Catcheway** Waywayseecapp Belina Clearsky

APPENDIX 2

DEFINITION OF DISABILITY

The World Health Organization (WHO) provides the following definitions for the terms impairment, disability, and handicap:

IMPAIRMENT: any loss or abnormality of psychological, physiological, or anatomical structure or function.

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

HANDICAP: a disadvantage for a given individual, resulting from impairment or disabilities, that limits or prevents the fulfilment of a role that is normal, depending on age, sex, social, and cultural factors, for the individual.

The term impairment addresses limitations or differences associated with an individual's psychological, physiological, or anatomic structure or function. A person with less than 20/20 vision has impairment in anatomical functioning.

The term disability refers to an individual's inability to perform an activity within the range that is considered typical for a human being. There are many different types of disabilities. Some leaders within the disability movement suggest that there is a disability for every organ of the body. Consequently, this manual does not attempt to list every disability. The definitions of impairment, disability, and handicap are included to provide an understanding of the experiences of people with disabilities within their social context.

The term handicap refers to the disadvantage that an individual experiences due to an impairment or disability. People who have visual disabilities talk about being "print" handicapped. According to the UN World Program of Actions Concerning Disabled persons,

handicap occurs when people with disabilities encounter barriers in the society in which they live.

People with visual disabilities experience a barrier when they want information and that information is available only in print. It is very difficult for the visually impaired to move freely about the community because most public information is made available to the community in the printed form only. When information is available in Braille, computer disk, large print, audiocassette, and barriers are eliminated for people with visual impairments.

The definition of mobility impaired includes persons restricted to a wheelchair because of paraplegia, quadriplegia, multiple sclerosis, etc., as well as persons who are not in wheelchairs, but have some difficulty moving freely about the community because cerebral palsy, arthritis, polio, etc. affect them).

The self-help movement of persons with disabilities advocates the self-Definition of disability; that is, it is the individuals who are experiencing limitations and barriers and should determine whether or not they want to define themselves as people with a disability.

DISABILITY AND PHYSICAL BARRIERS

A number of barriers exist within all systems of society - economic, political, social, recreational, service delivery, etc. There are attitudinal and cultural barriers, as well as structural barriers.

Stairs, for example, prevent the mobility-impaired from gaining entrance into many public buildings and places of residence. As a result, these people are severely limited in the services and types of accommodation they are able to choose. Many doorways are also often too narrow for wheelchairs to go through. Doors in many public places are too heavy and awkward for people in wheelchairs, or individuals with limited balance to open and pass through. The physical layout of buildings is also problematic. The aisles are often too narrow for wheelchairs to go through. Light switches are placed in the wall too high for persons in wheelchairs to reach.

Public transportation is inaccessible to persons in wheelchairs. Parallel transportation systems, if available, are too expensive, only run for a limited number of hours and, quite often, it is necessary for a person to book up to one week in advance in order to get an appointment. Hand controls for private vehicles are too expensive; the majorities of disabled persons are unemployed or can't afford to buy the car, let alone the hand controls.

Other barriers include the floor numbers in elevators, where they are given in printed form only, making it impossible for a visually-impaired person to identify the right button to push in order to arrive at the floor that he/she may desire. Nor will the individual be able to determine when the elevator has arrived at the correct floor. Signs and directives are used to direct traffic around public buildings, both of which are inaccessible to the visually

impaired. Most advertising is done in the form of newspapers and flyers. The heavy dependence on the print media makes it impossible for the visually impaired to become aware of and take advantage of the many sales that stores have. The price of merchandise in stores is given only in printed form making it impossible for the visually impaired to determine the price of goods without assistance. Canadian paper currency is all the same size making it difficult for a visually impaired person to determine the different values of paper money.

The greatest barriers to the hearing impaired are those related to communication. Because the majority of the hearing community does not use sign language, it is very difficult for a deaf person to communicate with a hearing person. As a result, the following activities that we take for granted are either unknown or very frustrating for deaf persons to participate in such as talking on the telephone, listening to the radio, watching television, going to the movies or to the theatre, dealing with sales people in stores.