Disability . . . it's not in me . . . it's out there.

A comparative ethnography of environmental factors influencing participation in three Baffin Island communities.

by

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Abstract

It has been well documented that Aboriginal Canadians experience higher rates of self-reported disablement than non-Aboriginal Canadians. In Canada's vast new territory, Nunavut, disablement exists for Inuit amongst unique cultural and environmental conditions. An ethnographic research project was undertaken in an attempt to understand, from the perspective of local residents and through analysis of the environment, how community participation could be enhanced for Inuit with disabilities living in three diverse Baffin Island communities.

A sample of convenience of thirty-four individuals with disabilities, caregivers of individuals with disabilities and community members from Iqaluit, Pangnirtung and Pond Inlet took part in focus groups and interviews over a six-month period. During this time, photographs, fieldnotes and documents contributed to the creation of a contextual representation of disablement. The study was conducted in Inuktitut and English.

Extreme ice, snow and cold temperatures limit physical mobility and outdoor safety for individuals with disabilities. In Iqaluit, poor accessibility and infrastructure compound this problem. Accessible transportation is a monumental barrier to participation in all three communities. The presence of an integrative attitude toward people with disabilities in Pangnirtung was a sharp contrast to the sense of isolation and perceived indifference from community members expressed by participants in Pond Inlet and Iqaluit. Suggestions for future action were sparse in Pond Inlet but focused on need for rehabilitation programs in Pangnirtung and the need for advocacy in Iqaluit.

The degree of exposure to Euro-Canadian values and systems may influence participation for Inuit with disabilities and how disability is perceived. Acculturation,

heterogeneity of the community, gender and socio-economic status may all have a significant impact on community participation for Inuit with disabilities. These are important considerations for program development and for guiding future research. Community-based Rehabilitation programs designed to enhance participation for Inuit with disabilities living in diverse Arctic communities should be based on suggestions, concerns and participation from local residents.

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First, I would like to thank the participants in Iqaluit, Pangnirtung and Pond Inlet for sharing their stories and welcoming me into their communities. I am greatly humbled by the profound wisdom offered incidentally through stories and encounters with people in each community. It is my hope that the journey toward sharing knowledge about disability in Inuit communities will continue to evolve for many years to come.

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Chapter 1

Introduction and Background

1.1 Introduction to Researcher and Statement of Problem

"Community outreach in the Arctic has cleansed and revamped my frame of reference for outreach rehabilitation services. It is apparent that cultural sensitivity must be the foundation of intervention programs here; geared to suit the needs of entire families living in isolated Arctic communities" (Robison, 1999). This excerpt reflects my sentiments in 1999 following a community visit to Pangnirtung. It was my first winter in Nunavut as the Baffin Regional Physiotherapist. This is a sole charge position that encompasses service provision for the capital city, Iqaluit, and ten other isolated communities. It was, and remains, the only locally based Physiotherapy position in Nunavut. I spent one year in this position.

An overflowing, unmanageable pile of referrals was normal. There was a waiting list that spanned months and it was commonplace to receive steady inquiries from the public, physicians and community health nurses. During community visits I saw Inuit [1] with disabilities living in what I believed to be appalling conditions, some whose equipment hadn't been replaced in two decades. Based on my outlook at the time, increased rehabilitation service and an expert opinion were tangible solutions to this problem. Furthermore, I believed that equipment should be used for its intended purpose... "A blood-tinged path to piles of frozen seals welcomed us to one home, a pediatric customized wheelchair standing only inches away – a surreal vision for any rehabilitation professional. We wondered if the chair, obviously not well used, was as frozen as the seals" (Robison, 1999).

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[1] Inuit: People inhabiting small enclaves in the coastal areas of Greenland, Arctic North America (Canada & Alaska) and extreme north-eastern Siberia.

I had the opportunity to reflect on my Baffin Island experiences after moving to Toronto in September 2000. The juxtaposition of cultures overwhelmed me to say the least. Ideals that were ingrained in my conscience about my role as a physiotherapist, theories of disablement and perception of health came immediately to the surface. It left me wondering if there was a bigger picture and a more holistic, inclusive way to explore disablement in Baffin Island.

After enrolling in graduate studies at Queen's University, an examination of the literature on this subject broadened my perspective. Disablement in the Canadian Inuit population exists amongst poor health indicators and complex socio-economic variables. Statistics, regional health surveys and assessment of need reveal a high prevalence of disablement in Nunavut (Baffin Regional Health Board, 1994; Canada, 1994; Miles-Tapping, 1989; Lutra Associates Ltd, 2000; Rokash, 2002). Most of these studies use numerical data to describe prevalence and assess need by breaking disability into quantifiable diagnostic categories. This is demonstrative of and synchronous with the medical model of health (Bickenbach, 1993b).

A social perspective of Inuit culture has not yet provided a foundation from which to describe the community experience of disablement, nor has the perspective of Inuit living with disability been the focus of research to date. Although disability has been documented in high proportions in Inuit communities, community profiles of disability that incorporate the context as well as the lived experience of disability have not yet been developed. Furthermore, the perspective from three geographically diverse communities in this enormous region may offer the greatest degree of insight on the subject. This, in turn, may foster the creation of more relevant, community specific health programs.

1.2 Study Purpose and Research Objectives

1.2.1 Study Purpose

I. The purpose of this study was to understand, from the perspective of Inuit and non-Inuit living in three diverse Baffin Island communities, how community participation could be enhanced for people with disabilities.

1.2.2 Research Objectives

I. The first objective was to establish descriptive community profiles of Iqaluit, Pangnirtung, and Pond Inlet that distinguish and describe the environment.

II. The second objective was to compare and contrast facilitators and barriers to community participation for individuals with disabilities living in these communities.

III. The final objective was to describe solutions for change from community members that would improve participation for Inuit with disabilities in the future.

1.3 Study Relevance

Extreme isolation alongside a complex web of historical, political and geographical forces make this Eastern Arctic region and the perspective of Inuit with disabilities who live here unique. Ethnographic investigation into Inuit community structure and the Inuit experience of disability is one step in a collaborative effort to enhance participation for Inuit with disabilities.

The Baffin Region is the largest in Nunavut but has received relatively little attention with regard to disablement. It is my hope that this ethnographic study has allowed Inuit with disabilities and community members to express their stories. My immersion in the region and previous experience has allowed me to have a greater understanding of the community

context. In doing so, it has allowed my assumptions and those upon which other service programs have been built on in the past to be re-evaluated.

Inuit with disabilities, caregivers and community members living in this remote location have had a voice to express their views in this study. Community representatives, Inuit organizations and the Government of Nunavut will hear this voice through feedback from the researcher. This will enhance understanding for government agencies and may assist in providing the missing foundation from which Community-based Rehabilitation (CBR) programs can be initiated.

A better understanding of disablement in Canadian Inuit communities will contribute to the body of circumpolar rehabilitation research. As a result, discussion about community development in isolated Canadian regions will be stimulated. This contribution may ultimately benefit all individuals affected by disablement in the Canadian Arctic.

Background

1.4.1 Nunavut (Our Land)

On April 1, 1999 the Nunavut Land Claims agreement was signed. A 1 925 460 square kilometer area which occupies twenty percent of Canada's land mass and is roughly the size of Mexico was transferred to the Inuit of Canada's Eastern Arctic (Nunavut Tunngavik Incorporated [NTI], 1998; Canada, 2001).

Evidence of mounting interest in Arctic development projects in addition to the unquestionable Inuit homogeneity of this region instigated this self-governing process (NTI, 1998). This agreement defined and legalized the relationship between the federal government and the founding Inuit of this area. Now, Inuit have control over wildlife, management, resource management, and environmental boards (NTI, 1998).

An elected premier operates within a public government using a consensus model of decision making while assuming responsibilities previously undertaken by the Government of the Northwest Territories. Nunavut Tunngavik Incorporated (NTI), an Inuit organization responsible for implementing the Nunavut Land Claim, monitors the capital transfer payments of 1.48 billion dollars and will continue do so over the next 14 years.

1.4.2 The Baffin Region

Physical and population geography

Nunavut is home to 26 745 people spread out in twenty-eight communities across three regions; Kivalliq (Keewatin), Qikitani (Baffin), and Kitikmeot (Canada, 2001). The most northerly community is Grise Fiord, located on Ellesmere Island and the most southerly point is Sanikiluaq, located in James Bay, south of Ontario's northern border (Roy, 2001). Inuktitut is one of three official languages spoken here and is the first language for seven out of every ten Nunavutmiut [2] (Office of the Languages Commissioner of Nunavut, 2003).

Baffin Island, is the fifth largest island in the world with a landmass of 507 241 square kilometers (Marsh, 1993). The Baffin Region encloses eleven communities nestled along its periphery and is home to fourteen thousand people. Eighty five percent of these people are Inuit Canadians (Canada, 2001). The geography of the island is diverse from north to south, and east to west. North Baffin, renowned for rugged inlets and towering cliffs, has been referred to as the least known, most spectacular fiord coast in the world (Bruemmer, 1993). Mountains and glaciers in the highland rim of the Canadian Shield span most of the east coast giving way to rolling tundra and plateau in the south and west parts of the island (Marsh, 1993; Grant, 2002).

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[2] Nunavutmiut: Inuktitut word for people who live in Nunavut

Temperatures here are consistently lower than in any other part of Canada (Environment Canada, 2003). For example, the average low temperature from December to May in South-eastern Baffin Island is - 24.2 degrees celcius. Comparatively, the average low for the same period in Southern Ontario is 5 degrees celcius. These temperatures combined with arctic permafrost, and relatively low precipitation result in slow growth of natural vegetation (Bone, 1992). Although this region is seemingly inhospitable, Inuit and their ancestors have lived on this land for over 4000 years, only recently experiencing changes that come with European contact and Euro-Canadian influence.

History & Culture

Dorset and Thule people, both ancestors of the modern day Inuit, traveled east across the Bering straight, into the Eastern Arctic to live in the present day Baffin Region between 800 BC and 1750 AD (Harper, 1993). Lifestyle here has fluctuated between nomadic and village existence, most often linked with abundance of whale but also dependence upon caribou, seal, walrus and fish subsistence.

Although sporadic contact with explorers has taken place from the sixteenth century onward, the infiltration of whaling stations and fur traders in the 1800's initiated what was to be the most profound impact on Inuit communities (Harper, 1993). Fur traders and whalers introduced the concept of a contractual system of economy that differed greatly from the Inuit system of sharing (Government of Nunavut [GN], 1998).

In the 1920's, the Canadian government attempted to solidify its sovereignty claim over the arctic by setting up Royal Canadian Mounted Police detachments to patrol the area (Harper, 1993). Hudson's Bay trading posts were also established in communities around this time in order to exchange goods more consistently with Inuit. According to Inuit

Quajimanituqangit (IQ) [3], families became less self-reliant as a result and gravitated away from movement and leadership based on food availability (GN, 1998). Simultaneously, missionaries were establishing Christianity, basic medicine and introducing the syllabic writing system. This presented a contrast to traditional oral history, shamanism and traditional healers (GN, 1998; Grant, 2002).

During World War II, Iqaluit became a focal point for construction of a Distant Early Warning (DEW) Line on Baffin Island and a military airstrip was built there. In the 1950's children were moved from traditional camps to federal schools built in the communities. In most cases their families followed. In some instances, children were removed from their communities to residential schools in the South. In the mid 1960's houses were built in the communities to accommodate Inuit families and their children. Traditional life in camps was forever altered at this point as Inuit became permanent residents in Baffin Island communities (Harper, 1993).

[3] Quajimanituqangit (IQ): Inuktitut word for "Traditional Inuit Knowledge"

Chapter 2

Literature Review

2.1 Introduction to Aboriginal Disablement in Canada

The government of Canada acknowledged in December 2002 that information about Aboriginal [4] persons with disabilities was severely limited (Canada, 2002). As a result, the aim of the latest federal mission statement is to ... "make it a priority to remove barriers to full participation for persons with disabilities by the 21st century" (Canada, 2002, p.1).

The mainstay of literature on this subject uses the 1991 Aboriginal People's Survey (APS) as the benchmark for published reports. In this report, thirty-one percent of Aboriginal adults described some level of disability whereas fifteen percent of Canada's total adult population made this claim (Canada, 1994). Frankel (1998) suggests in his Background Paper for the Aboriginal Reference Group on Disability Issues that this survey did not comprehensively describe the social and economic characteristics of Aboriginal people with disabilities. Furthermore, The Royal Commission on Aboriginal Peoples (1996) stated that debilitating social conditions may be a primary cause of this disparity, compounded by inadequacies in service provision and ignorance of cultural needs.

Health trends and socio-economic factors in Aboriginal communities create a context for this increased incidence of disablement. National statistics combined with regional investigations delineate the scope of this disparity. Service delivery trends in aboriginal and Inuit communities *have* touched on alternative methods of delivering service to remote communities. However, the issue has not yet been adequately addressed based on the

[4] "Aboriginal" is used in the academic literature to describe Inuit, Metis and First Nations people of Canada. Where possible in this paper, there will be a distinction made between First Nations and Inuit people.

expressed needs of people living with disability and on the unique context of Arctic communities. Furthermore, disability theory emphasizes the importance of a thorough analysis of cultural and social conditions when attempting to accurately depict disablement.

2.2 Health Status of Aboriginal Canadians

2.2.1 Emergence of Chronic Disease

It has been well documented that Aboriginal Canadians experience poorer health than that of non-Aboriginal Canadians (Macmillan et al., 1996; Newbold, 1998; Young, 1994). Literature profiling the emergence of chronic disease, prevalence of lung cancer and high incidence of injury and suicide is now abundant (Anand, 2001; Bjerregaard, 2001; Bjerregaard & Young, 1998; Government of Nunavut, 2002; Peschken & Esdaile, 1999; Rode & Shephard, 1995). Chronic diseases are presently lower in circumpolar regions than the Canadian average but they are increasing due to changing life styles and environmental pollution (Bjerregaard, 2001; Bjerregaard & Young, 1998; Young, Szathmary, Evers, & Wheatley, 1990). Definitive links between these trends, socio-economic status and disablement have not yet been established in Inuit communities.

2.2.2 Social and Economic Factors

It has been well documented that people with disabilities experience greater socio-economic disadvantage in Canada (Canada, 1998; Fawcett, 1996; Ng, 1996). This phenomenon has also been established in First Nations populations of Canada. In an ethnographic account of the First Nations Population of the Mushkegowuk region of Ontario, the author felt that economic hardship and complex co-morbidities compound existing impairment associated with disability (Robarts, 2002). Similarly, a qualitative study of urban First Nations people with disabilities entitled "Triple Jeopardy" describes poverty, poor

health, and decreased economic opportunities as factors that are linked with disablement (Durst & Bluechardt, 2001). A link between these two phenomena has not been established in the Inuit populations of Nunavut.

It has, however, been established that poor socio-economic conditions do exist in Nunavut. The 2001 census documented an unemployment rate of 16 % in the Baffin Region compared with a national unemployment rate of 7.4 % (Canada, 2001). Family violence and sexual abuse are also deemed by Inuit communities to be problem. In 1991, 43% of Inuit felt that family violence was a problem and 35% felt sexual abuse was a significant community problem (MacMillan et al., 1996).

On a similar note, inadequate housing in Aboriginal communities has also been well documented in the literature. The 1991 Aboriginal People's Survey (APS) provided housing characteristics of individuals who reported Aboriginal identity (Canada, 1994). The average number of people per dwelling was 3.5, slightly higher than the 2.7 persons per dwelling among Canada's total population. Twenty percent of these dwellings were in need of major repairs compared to eight percent of Canadian dwellings. Results from a Northwest Territories Housing Needs Survey published in 1992 also yielded higher numbers of people per dwelling and greater need for major repairs (Northwest Territories Housing Corporation, 1992).

Housing has been linked to health in Arctic Canada. A study investigating the impact of housing on health looked at community-level data on various housing indicators from the NWT Housing Needs Survey and linked this to other community level data (Young & Mollins, 1996). This study found a moderate correlation between housing conditions and health centre visits and a strong association between socio-economic status and health. In

response to a critical housing crisis, the national organization, Inuit Tapirisat of Canada (2001), commissioned a study on National Inuit Housing. Survey responses from elders [5] highlighted that inadequate housing increased the number of family break-ups while exacerbating health problems. Accessibility conditions associated with mobility limitations were not assessed.

The research clearly demonstrates that social and economic well-being in Inuit communities pales in comparison with that of the average Canadian. However, it is difficult to discern from this research how the socio-economic environment interacts with disablement to affect participation for Inuit people with disabilities.

2.3 Disability Research: Aboriginal and Inuit Communities

2.3.1 Incidence and Distribution of Disability

The 1991 Aboriginal People's Survey (APS) for disability and housing used a sample of 65 500 from the 1991 census aged 15 and over who reported Metis, Inuit or North American Indian Ancestry on their census form (Canada, 1994). Approximately 10% percent of those surveyed reported Inuit ancestry, most of whom were Labrador Inuit. Nunavut was not a territory at the time of the survey and it is unclear if any of the communities in the Northwest Territories were surveyed. At the same time, a Health and Activity Limitation Survey (HALS) was conducted in a sample of 91 400 non-Aboriginal Canadians (Canada, 1991). The survey methods for assessing disability were identical.

In both surveys, personal interviews were conducted in order to determine prevalence and severity of disability and degree of dependence (Table 1). Respondents were asked questions

[5] "Elder" is the word used in Inuit culture to describe a wise individual. An elder is greatly respected for his/her knowledge and community members' often seek guidance from this person. This wisdom usually comes with age.

about self-perceived limitations (lasting >6 months) in sensory, mobility, agility and other physical and psychological abilities. A person who was limited in any of these activities, even with a specialized or technical aid was considered to have a disability. Severity of disability was determined for 23 activities. A score of 1 was assigned for partial loss of function and 2 for total loss of function. A person with a total score of 1-4 was considered mildly disabled: 5-10 moderately disabled; and 11 or more, severely disabled.

Table 1: Inuit and Canadian Disability Data. Adapted from the Aboriginal Peoples Survey (APS) and the Health and Activity Limitation Survey (HALS) (Canada, 1994; Canada, 1991a).

Survey Area	Inuit	Canada
Self Reported Disability	**29%**	**15%**
	⇩	⇩
Limitation in:		
Mobility	36 %	45 %
Agility	26 %	44 %
Hearing	44 %	23 %
Seeing	24 %	9 %
Mild Disability	74 %	60 %
Severe Disability	8 %	12 %
Need help with everyday housework, shopping and groceries.	17 %	18 %
(Percent of above getting help)	(96%)	(81%)
Need help with heavy household chores.	25%	31%
(Percent of above getting help)	(92%)	(89%)
Difficulty Taking Short trips	11%	Data not
(Ratio of above - Unable to leave home)	1/3	available.

This survey demonstrates that disablement is twice as prevalent in the Inuit population of Canada. It appears from these data that people with disabilities receive help with activities of daily living. When it comes to leaving their homes, however, it appears than many Inuit with disabilities have difficulty. It was successful in demonstrating that a problem exists but insight into why people are unable to leave their homes was not provided.

Regional studies within specific Aboriginal populations have also been carried out. The First Nations, Nuu-Chah-Nulch population of British Columbia reported that 30% of people experience an activity limitation (Nuu-Chah-Nulch Health Board, 1989). Similarly, a study carried out in a First Nations population of Northern Ontario found that 12.1 % of children under fifteen had a disability (Larson et al, 1986). In the 15-34 age category, 25.2 % experienced a disability.

2.3.2 Prevalence and Distribution of Disability in Canadian Arctic

Several investigations have been done in the Canadian Arctic that document a high prevalence of disablement. Statistics collected in a population survey of the Keewatin region of the Northwest Territories stated that a disability prevalence of 26% existed (Miles-Tapping, 1989). Comparably, the Canadian prevalence in 1991 was reported to be 15% (Canada 1991). A study in the Baffin Region that looked at the prevalence of disability and congenital abnormalities in the pediatric population by distributing surveys to health centres found that 14% of children in the Baffin Region had a physical or sensory disability (Destounis et al, 1991).

Furthermore, unmet needs were recognized in the Baffin Region in 1994 when the Registry for Persons with Disabilities in the Baffin Region identified 127 children, 55 adults, and 69 elders as having unmet needs requiring rehabilitation services of physiotherapy, occupational therapy, and speech and language therapy (Baffin Regional Health Board, 1994). This survey also documented that each community had a minimum disability prevalence of 10% and that 41% of all chronic disabilities in the Baffin Region were neurological or sensory impairments.

One major limitation of this research is that it was executed through health centre staff. Presumably many individuals with disabilities may not visit the health centre and therefore may not be included in the number of individuals with disabilities. Despite the recognition that there was a high prevalence of disablement in this region, the perspective of Inuit living in Baffin Island communities was not addressed.

2.3.3 Assessment of Need in the Northwest Territories and Nunavut

In 1998, a health executive established a work plan to develop a regional rehabilitation program (Watts, 1998). In this proposal, it was stated that rehabilitation services were one of the most under-funded and underdeveloped health and social services program areas in the Baffin Region. It was recommended that improvement of health and independence of Baffin residents would come through provision of rehabilitation services.

An abilities conference was one portion of the Future of Work in Nunavut Conference held in 1998 (T-based Research & Development Inc., 1998). Here, Inuit with disabilities spoke at length about their experience with disablement and personal barriers to participation. Many gave emotional descriptions of financial barriers to participating in traditional activities like hunting and camping and their exclusion from Hunter Income Support policies due to physical limitations. Issues related to lack of employment and overstressed caregivers were raised at this time. The "Nunavut Council for People with Disabilities" was subsequently established. The hope was that Inuit with disabilities would be able to discuss their desire to participate as full and equal members of society. This Council *was* created by an Inuit organization and went bankrupt in 2002.

A consultancy was hired in 2000 to conduct a survey of 1 259 people living in the NWT who were affected in some way by disability (Lutra Associates Ltd, 2000). Four hundred and

nine of these were caregivers, community service providers and regional program managers. Eight hundred of these people reported having a disability of which 64% reported a physical limitation. The assessment found that adults and elderly persons with disability are mainly engaged in work in the home including sewing/or harvesting-land based activities.

Two thirds of persons with disabilities believed that programs and services did not meet their needs due to lack of awareness and sensitivity to Aboriginal customs/language, lack of access, and lack of understanding, support and recognition of disabilities. Rehabilitation programs/services were in greatest demand followed by financial assistance, advocacy and information. Persons with disabilities reported experiencing a limitation regardless of whether or not special aids and supports were in place. This leads one to question what other issues exist that limit participation.

This survey appears to demonstrate an accurate portrayal of relevant issues for Aboriginal individuals with disabilities living in NWT. However, the Northwest Territories are comprised of an equal proportion of Aboriginal and non-Aboriginal people. Also, within the Aboriginal distribution, there are Western Arctic Inuit, Dene, and Cree people. Presumably, the perspective of these individual groups in various regions was not captured by this survey. High relevance is placed on categorization of disabilities and discussion was guided accordingly. The interaction of other factors at a community level that may contribute to limitations was not represented.

The Government of Nunavut executed an Assessment in 2002 in order to identify need in the areas of audiology, occupational therapy, physical therapy, speech language pathology, and dietetics (Rokash, 2002). The Baffin and Kitikmeot regions were the focus of this assessment. Large focus groups, individual interviews and review of existing programs were

the methods used to collect this information. Fifty-five participants participated in focus groups. Twenty were health professionals, nineteen were employed by health or education, twelve were community members and four were people with disabilities. Of forty-nine people informally interviewed, thirty-two were health professionals and seventeen were community members.

It is evident that the majority of survey recipients and focus group participants were individuals employed in health centres and schools whereas health professionals made up most individual interviews. Rokash (2002, p. 8) states that . . . "rehabilitation services offered at the community level are extremely limited under the government of NWT and continue to be so since the creation of Nunavut". This author also describes the model of service delivery as primarily a consultative one with limited outreach services to the communities. In addition to recommending increased service provision, the author places several priorities on these services; increased public awareness of roles of rehabilitation professionals, use of a multidisciplinary team approach, greater collaboration between departments, and more efficient integration and co-ordination of rehabilitation services.

Furthermore, enhanced community level services would occur through funding for community outreach services, greater number of visits by health professionals, creation of rehabilitation assistant positions, greater use of telehealth and more frequent periods for consultation. This assessment was effective in reinforcing the need for rehabilitation services, however, the term "Community-based rehabilitation" appears misplaced in light of the minor role of individuals with disabilities at a community level. There was a focus on existing program weaknesses and infrequent mention of community strengths. Furthermore,

the broad range of topics addressed limits how specific programs can be tailored to meet the needs of people in each Baffin community.

A similar needs assessment was completed in the Kivalliq region of Nunavut in 1999 (Fricke, 1999). Subsequently a training program was initiated through the Northern Medical Unit at the University of Manitoba (University of Manitoba, 2003). A curriculum is presently being developed to train local rehabilitation assistants at the Arctic College in Rankin Inlet (personal communication, M. Achtemichuk, 18 July, 2003).

The issue of disablement in the Baffin Region has received sporadic attention over the past ten years with an evident progression from disability statistics to assessment of need. These needs assessments have largely excluded input from Inuit with disabilities living in these communities. Furthermore, the effectiveness of "outsiders" delivering rehabilitation services has not been considered nor have Inuit values been included in assessment of cultural appropriateness. Government agencies appear to be establishing medical rehabilitation service needs based on a frame of reference that originates from Southern Canada whereas Inuit express their needs through oral accounts of personal experience in their communities. These two perspectives may be quite different.

2.3.4 Rehabilitation Program Delivery in Aboriginal Communities

Integration and co-ordination of rehabilitation service delivery for Aboriginal people has been identified as a significant barrier to community participation for people with disabilities (Newbold 1998; Ng 1996; Canada, 1993; Rokash, 2002). Culturally inappropriate service provision and lack of consumer input into health provision were described as key contributing factors to this discrepancy. Ignorance of service providers to the intrinsic dependence on family and community members for assistance with activities of daily living

and functional mobility tasks is also problematic (Blackmer & Marshall, 1999). Marshall and Johnson (1995) document this concern in their comprehensive chapter on rehabilitation services and American Indians. They encouraged rehabilitation professionals to . . . "appreciate and recognize the value of community knowledge in culturally appropriate rehabilitation service delivery" (Marshall and Johnson, 1995, p. 257).

Thibeault (1997) cited the model of care in Pelly Bay, Northwest Territories. Here, health care is delivered through local health centres staffed with nurses, community representatives and visiting health professionals. A similar model of rehabilitation service delivery exists in neighbouring Baffin Island (Rokash, 2002). These are examples of instances where the non-Inuit health professional typically bases treatment intervention on a Western ethno-medical model of care (Fricke, 1999). In fact, Fricke states that . . . "the existing system available to Aboriginal people with special needs has often resulted in an unaccountable and ineffective web of service delivery" (Fricke, 1998, p.723).

Few CBR programs have been developed in Canadian Aboriginal communities. Community-based Rehabilitation involves taking measures to use and build upon resources at the community level, thus allowing people with disabilities to be participants in the social and economic activities of their society (World Health Organization [WHO], 1991). Canadian researchers have predominantly focused on international CBR initiatives and Nunavut has seen only glimpses of this model. However, research in Canadian First Nations and Inuit communities is moving toward community action plans and participation.

Robarts (2002) executed a qualitative study exploring the needs of people with disabilities living in the Mushkegowuk Territory of Ontario. This participatory ethnographic research was successful in combining a cultural perspective that provided a foundation for service

delivery. Subsequent curriculum development and implementation of the "Community Rehabilitation Aides Project" was based on target areas revealed in this assessment that would yield the greatest impact and ameliorate disability (personal communication, L. Tata, 19 July 2003). The completion of six group-teaching modules of one-week duration will be completed in 2003/2004. These modules focus on disability management (assessment and intervention), neurological disability, mental health, administrative skills and management skills. Evaluation of program effectiveness will occur in the upcoming months.

One CBR program has been examined as a viable alternative to the present model of service delivery in the Kitikmeot region of then Northwest Territories and presently Nunavut. Between 1991 and 1993, success was documented in a CBR initiative targeting Inuit children at risk for developmental or learning delays (Thibeault, 1997). Two people were hired to work with children, and offered a two-week training program with an Occupational Therapist and consultant. Children were seen twice in their homes with their family for the duration of the program. Three marked benefits were described at the outset of the program. These children took a more active part in community life; employment and educational opportunities were created, and communication between local and government agencies was fostered. Thibeault describes a successful CBR program but emphasizes that research avenues to provide a more extensive theoretical background for implementation of CBR programs in similar communities would be beneficial.

A synthesis of selected community consultation documents from 1993 onward was prepared for the Government of Nunavut in 1998 in order to develop policies and programs that reflected the views, needs and understandings of Nunavut residents (Schaaf, 1998). Five themes were generated for consideration in future program and policy development: cultural

preservation, increased inter-departmental co-operation, fostering ongoing community consultation, and enhancing community leadership through ongoing community consultation.

Fricke also notes that consumer empowerment and self-determination as focal points of research with Aboriginal people will contribute to improvements in health status (Fricke, 1998). It is important to examine the reticence of First Nations and Inuit Canadians to embrace a medical service delivery model and prioritize consumer input as a foundation for future program development. The evolution of disability theory toward describing an individual's ability to participate within a social context presents a foundation for study that goes beyond traditional medically based intervention.

2.4 Disability Theory

2.4.1 Social Theory of Disablement

In the past, disablement has been based on a framework of linear, causal relationships between disease and disability (Simeonsson et al, 2000). This model describes disability as a deficiency, dysfunction or abnormality that is located at the level of the individual (Bickenbach, 1993a). As a result, the era of modernism has seen the concept of normative assessment of an individual's abilities become orthodox (Kasonde-Ng'andu, 1999).

Disability advocates and academics have changed the way disability is now theoretically described. The social model of health emphasizes that unique cultural and social environments, and capacities most prized within this context, are critical to understanding individual and community experiences of disablement (Ingstad and Whyte, 1995). Bickenbach emphasizes this point. He states that experience can be . . . "altered, remedied or ameliorated without making change in the physical condition of the individual" (Bickenbach, 1993b, p. 137).

In Marks' (1997) article on models of disability, medical approaches are critically reviewed. The concept of disability being located at the level of the individual person and being compared to a normal level of function is challenged. She suggests that a shift in emphasis to the relationship between people and their social environment will allow changes to be made in social policy, culture and institutional practices. She goes on to say that social organization, not physical dysfunction, has the power to oppress people (Marks, 1999).

The International Classification of Function was published in 2002 by the World Health Organization (WHO) and is based on disability theory represented by Bickenbach, Chatterji, Badley & Ustun (1999) and Zola (1989). These authors suggest that disability is a universal

feature of the human condition that depends on the physical and social environment in which an individual is placed (Bickenbach et al, 1999; Zola, 1989). Although this universal language may allow allied health professionals to define specific practice concerns and establish research priorities, it still possesses medical undertones. Loss or deviation still rests at the level of the individual and, hypothetically, all individuals can be placed into groups. The environment makes up a more peripheral part of the document. The practical use of this document to describe the needs of indigenous Canadian communities is therefore limited.

The social model of health is the most relevant theoretical underpinning for investigating and discussing disablement in remote Inuit communities. Evidently a high incidence of self-reported disablement exists in Nunavut. From the literature on this subject, it is difficult to discern what the boundaries of this perceived limitation are. The social model of health allows for a more contextual investigation of facilitators and barriers to participation.

2.4.2 Occupational Therapy Theory

Models of Occupational Performance provide a more in depth framework for describing the cultural environment. Occupational Therapy theory is based on the philosophical assumption that ... "an individual can neither be understood nor assisted toward a more adapted mode of behaviour without consideration of the environment" (Mosey, 1998, p. 171). The cultural, social and physical environments in which a person functions have been described by many researchers as critical to understanding occupational performance (Law, 1991; Dunn, Brown, McGuigan, 1994; Grady, 1995; Townsend et al, 1997; Rebeiro, 2001; Kielhofner, 2002;). Law states that these environments can both help and hinder satisfactory occupation (1991).

Human occupation is described as engagement in work, play and activities of daily living within a temporal, physical and socio-cultural context (Townsend et al, 1997). "Occupational Participation" in this context is engagement in life situations that encompass productivity, leisure and self-care (WHO, 2002; Kielhofner, 2002). Kielhofner also emphasizes that occupational participation should include the socio-cultural context and enhance one's sense of well-being.

The Ecology of Human Performance (EHP) is a framework for analyzing the effect of context. The author states that the interrelationship of person and context determines which tasks fall within an individuals' performance range (Dunn et al, 1994). In this model tasks are defined as objective sets of behaviours necessary to accomplish a goal. In performing tasks, people use environmental cues and features to support performance. The author likens context to a lens in which individuals see the world. People use their skills and abilities to look through a lens at the tasks they need or want to do.

The capacity of one to use skill and ability to participate in a community setting requires careful examination of cultural, social and physical environments. This Occupational Theory provides a guiding framework for investigation of the cultural environment in the Baffin Region as it relates to people with disabilities.

2.4.3 Disability and Culture

Definitions of disablement may vary across cultures that have diverse social and economic profiles. Culture is defined as "the behaviour of contemporary people: their customs, beliefs, values and social interactions; the physical products of their minds and hands; and the ways in which they communicate with one another" (Hicks & Swynne, 1994, p. 3). An Australian ethnography examining how disability is constructed through Anangu

culture, language and history found that disability was constructed socially, not by a defined limitation (Ariotti, 1999). Ingstad, a prominent researcher in cross-cultural interpretation of disability, reiterates and extrapolates on this concept, stating that... "social circumstances combined with cultural beliefs provide a foundation upon which rehabilitation programs should be built" (Ingstad, 1990, p. 18). Similarly, Leavitt (1992, p. 19), a professor of medical anthropology at the University of Connecticut describes the presence of disability as . . . "an observable phenomenon in all societies, the significance of which is dependent upon the society's cultural rules" (Leavitt, 1992, p. 19).

It is evident that social and cultural beliefs of a society are integral to understanding disablement. It is therefore imperative to achieve a preliminary understanding of Inuit cultural values in order to create a point of reflection for holistic accounts of disablement in this region. Inuit cultural values will dictate what constitutes participation for individuals with disabilities and provide a foundation from which to describe community life. The Bathhurst Mandate provides an outline of such values as they pertain to health in a detailed plan with objectives for Nunavut's future (Government of Nunavut, 2003). In this highly referenced document, serving Nunavut in the spirit of *inuuqatigiitiariniq* refers to the healthy inter-connection of mind, body, spirit and environment. According to Inuit Traditional Knowledge, the essence of Inuit culture is a set of four basic relationships with land, family, one's inner spirit and one's social group (Pauktuutit, 1998). These relationships are outlined in Table 2.

Table 2: Four basic relationships that make up traditional Inuit Knowledge (Adapted from Pauktuutit, 1998)

Relationship with the Land	**Avatittinnik Kamattiarniq- environmental stewardship Qaunuqiuurniq – resourceful to solve problems and improvise with what is at hand as a source of fulfillment and self-realization**
Relationship with one's family.	**Pijitsirnjiq – serving and providing for. Expresses obligation and responsibility to family and its survival**
Relationship with one's own inner spirit.	**Pilnimmaksarniq – passing on of knowledge and skills through observation, doing and practice. Skill development and knowledge acquisition strengthens a personal sense of identity.**
The Relationship with one's own social grouping and between social groupings.	**Piliriqatigiingiq – concept of collaborative working relationships or working together for a common goal. Qajiiqutigiingniq – Inuit decision-making. Comparing view, taking counsel or consensus decision-making.**

These guiding principles may be evident in community participation within Baffin Island Communities. Modern Inuit live according to values that arise out of their tradition (Pauktuutit, 1998). They continue to have a tie with the land and consider their relationship to the land to be essential to their culture and survival (Pauktutit, 1998). Although it is evident that a discrepancy exists between Aboriginal and non-Aboriginal disablement status, cultural factors and social context as they may relate to disability have not been considered to date in the Inuit population of Canada.

Chapter 3

Methods

3.1 Rationale for Ethnographic Research Design

3.1.1 Paradigm Selection

The interpretive research paradigm provided a theoretical foundation for this ethnography. This is the epistemological stance that attempts to interpret a social groups' meaning of reality (Schwandt, 2000). In a framework for research implementation and reporting, Higgs (1998) describes the research goals that are cohesive with this paradigm. She states that these goals should seek to understand, interpret, seek meaning, describe, illuminate and theorise. As such, the researcher will attempt to interpret the phenomenon of disablement in the Inuit culture based on the research objectives listed in Chapter 1.

3.1.2 Research Methods

An ethnographic research design is typically chosen in order to explore a phenomenon within a culture from an insider or *emic* perspective (Hammersley & Atkinson, 1995; Fetterman, 1998). An ethnography also provides factual description and analysis of aspects of the way of life of a particular culture through physical association (Germain, 1993). Ethnography was chosen to address research questions that seek to interpret and illuminate the Inuit experience of disablement within a cultural and social context.

Disability theorists urge researchers and policy makers to consider describing disability as it exists within one's environmental context (Bickenbach et al, 1999; Fougeyrollas, 1995; Ingstad, 1990; Marks, 1997). This is consistent with the holistic nature of ethnography in which the researcher explores a phenomenon as it interrelates among politics, economy, environment and history of a region (Fetterman, 1998). In an article on indigenous

approaches to disability, the author goes further than recommending inclusion of the environment and comments on useful methodologies: "Another way forward is to embark more on anthropological methodologies in our research in the field of disability. We need to learn more about different cultures in the context of disability" (Kasonde-Ng'andu, 1999, p. 120).

Similarly, Harris (1992) promotes naturalistic inquiry as the paradigm of choice for community development. He states, "naturalistic inquiry is the paradigm of choice for social phenomenon reflecting the complex lived reality and interwoven factors" (Harris, 1992, S63). Holistic inquiry reflects objectives outlined in the Bathhurst Mandate. In this document, the health of Nunavut is deemed to be dependent on the health of each of its physical, economic and cultural communities, and the ability of those communities to serve Nunavummiut (Government of Nunavut, 2003).

Ethnographic research, through its close interactive relationship between the researcher and the participant, respects bioethical principles for clinicians in Aboriginal cultures as outlined by Ellerby et al. (2000). Preservation of culture is a crucial component of ethnography that is reflected in Grey's account of her experience on Baffin Island. She states that it is evident that the Inuit want to preserve their customs and values and make them the underpinnings of any future programs (Grey, 1996).

3.1.3 Other Similar Research Methodologies

Research in Aboriginal communities is starting to embrace ethnographic methods. Bosten et al (1997) examined meaning attributed to rising incidence of diabetes in Cree communities through an ethnographic participatory action research design. An ethnographic research project was recently executed that explored disablement in First Nations Communities

(Robarts, 2002). People living in remote communities of the Mushkegowuk territory of Ontario worked closely with the researcher and local research assistant to express their own disability related needs and create more culturally relevant constructions of disability.

Ethnographic studies have been done internationally that demonstrate the efficacy of this method. In Ingstad's narrative description of people with disabilities in Botswana, for example, she dispels the myth that family attitudes are the source of oppression here for disabled people (Ingstad, 1995). The author does this by exploring the social context through ethnographic methods. In an account of disability in the Andes, Rosing (1999) found that choosing modernity *or* tradition may not be the answer to assisting people with disabilities. Instead, during her long period of immersion, she assessed cultural resources and barriers for people with disabilities.

Despite the convincing rationale for this approach, ethnographic studies where disability is explored in Aboriginal Canadian communities are extremely rare. International ethnographic studies demonstrate how effective this methodology can be in dispelling myths and enhancing understanding of disablement. Furthermore, there has been no qualitative research to date that seeks to understand disablement from the perspective of Inuit living in circumpolar regions through qualitative investigation.

3.2 Initial Phase of Fieldwork

3.2.1 Preparation and Establishing Contact

Familiarity with the region through one year of previous physiotherapy work experience in Iqaluit eased the transition to fieldwork for the researcher. Six months of full-time physiotherapy employment with Baffin Regional Health and Social Services was easily arranged prior to the planned departure for Nunavut. This employment financed a six-month

stay in the field for the researcher and served as one source of entry to the communities. Baffin Regional Health and Social Services provided financial support for two fieldwork trips. A Northern Scientific Training Program Bursary (NSTP) of $3800 through the Department of Indian Affairs and Northern Development (DIAND) was transferred to a research account in Iqaluit. This was used for partial coverage of the cost of translation, food and accommodation in the field.

During the initial phase of fieldwork in Iqaluit contact was established with an Inuk [6] co-worker who was an informant about disability in Iqaluit and an invaluable interpreter. Advice was given on cultural nuances throughout the interpretation of consent forms, confidentiality agreements, radio advertisements, and written advertisements.

3.2.2 Ethical Considerations

During this phase, letters were sent to community hamlet offices in Pond Inlet and Pangnirtung and follow-up phone calls were made. A Canadian Broadcasting Corporation (CBC) radio "health spot" was done to discuss disablement in the region, describe the research study and to recruit participants. Health Centres were also called and informed of the research study. Nunavut Research Institute (NRI) license approval and Queen's Ethics approval were granted during this time (Appendix A). The NRI ensures that the study meets ethical guidelines set out by research policy makers in the North as well as ensuring that Nunavut groups are informed and invited to participate.

A meeting with two representatives from the Qikiqtani Inuit Association (QIA) was held to describe the present research and secure a partnership for future action. The Qikiqtani Inuit Association is a community non-profit organization that works with government to promote Inuit benefits and to establish Inuit rights.

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[6] Inuktitut: One Inuit person. In context it may be used as follows: "I am Inuk" or, "She is Inuk".

3.3 Sampling

3.3.1 Community Sampling

Iqaluit, Pangnirtung and Pond Inlet were chosen based on geographic diversity of location, size and development status. Iqaluit, the largest community, is located in South Baffin. As the capital city of Nunavut, it is considered to be the hub of political and economic activity. Pangnirtung is known for its Arts and Crafts Centre, and nearby National Park where many tourists visit each year. Pond Inlet is approximately the same size as Pangnirtung but is located at the extreme north of Baffin Island. People consider this community isolated and traditional with few economic opportunities.

Community representatives were contacted through the Nunavut Research Institute. The English/Inuktitut consent forms were reviewed by the local hamlet councils and permission was granted to carry out research in Iqaluit, Pangnirtung and Pond Inlet. In addition, the researcher discussed the project by telephone and by email with representatives in Pangnirtung and Pond Inlet. During the researchers initial visits to Pangnirtung she met with the mayor and while in Pond Inlet, participated in a Hamlet meeting.

3.3.2 Participant Recruitment

Thirty-four participants were recruited through a sample of convenience in Iqaluit, Pangnirtung and Pond Inlet during a six-month fieldwork period. These individuals were greater than eighteen years of age and demonstrated a desire to participate in the study. Caregivers, people with disabilities and community members were sought through criterion based and purposive sampling (Kuzel, 1999). Inclusion criterion and sample characteristics are listed in Table 3.

All Inuit participants were offered the choice of participating in a focus group and/or in an interview. Non-Inuit participants were excluded from focus groups when possible in order to obtain a more culturally relevant depiction of factors influencing disablement. In all but two cases, non-Inuit participants were health professionals.

Table 3: Inclusion Criteria.

Participants	Inclusion
People with Disabilities	**>18 years old** **Experience a functional limitation that affects physical mobility.**
Caregivers	**Family Members** **Informal or formal caring for person with functional limitation.**
Community Members & Health Care Providers	**Health Care Providers with > 3 years experience in the North** **Key Informants in the Community**

Radio announcements, and posted advertisements in health centres were used to recruit participants (Appendix B). Participant recruitment snowballed (Kuzel, 1999) as local informants contacted people and described the project to them. As the study progressed contacts were made with key informants in each community, at health centres and in hamlet

offices. In this way, opportunities were created to recruit subjects. After an individual showed interest in participating, he/she was presented with more detailed information. Prior to the interview or focus group, an approved Inuktitut/English consent form (Appendix C) was provided to each participant and time was given to read the form and ask questions. The importance of confidentiality was discussed with interpreters and a confidentiality agreement (Appendix C) was signed prior to the commencement of translation.

3.3.3 Participants

The total number of participants was thirty-four. This was a sample of convenience and these were the only participants recruited for the study. Table 4 summarizes participant characteristics by community. Nine participants were caregivers and twelve were community members. Thirteen people had disabilities; eight female and five male. Eleven of these were Inuit and two were non-Inuit. Eight participants in this group were unilingual Inuktitut speakers, three were fluent in English *and* Inuktitut and the two non-Inuit participants spoke only English. The average age was fifty-seven and the median age was sixty-two.

All five participants with disabilities in Iqaluit were female. The average age was fifty and the median was forty-nine. The youngest participant was twenty and the oldest was seventy-four. One non-Inuit woman participated. Of the other four, two were bilingual in Inuktitut and English and two spoke Inuktitut. Four female caregivers took part in Focus Group I. Three people spoke Inuktitut and English and one spoke Inuktitut. Three non-Inuit community members participated in interviews; The Iqaluit Homecare Co-ordinator, the Regional Nutritionist, and the Director of Economic Development and Tourism for the department of Sustainable Development in the Government of Nunavut.

Table 4: Participant Characteristics by Community

Community/ People with Disabilities (PWD), Caregivers, Community Members	Age	Sex	Ethnicity/ Language Inuktitut: I English:E	Impairment	Employment
Iqaluit	20	F	Inuit: I/E	Cerebral Palsy	
	59	F	Inuit: I	Post-polio Syndrome	
	49	F	Inuit: I	Psoriatic Arthritis	
PWD	74	F	Inuit: I/E	Stroke	
n=5:	46	F	Non-Inuit:E	Rheumatoid Arthritis	
Caregivers	38	F	Inuit: I/E		Children's Group Home
n=4:	52	F	Inuit: I		Homecare Worker
	32	F	Inuit: I/E		Homecare Worker
	37	F	Inuit: I/E		Children's Group Home
Community Members n=3	50	M	Non-Inuit: E/I		Director Tourism & Economic Development
	28	F	Non-Inuit: E		Regional Nutritionist
	47	F	Non-Inuit: E		Homecare Co-ordinator
Pangnirtung	62	M	Inuit: I	Neurological Impairment	
	58	M	Inuit: I	Post-polio Syndrome	
PWD	78	F	Inuit: I	Osteoarthritis	
n=3					
Caregivers	51	F	Inuit: I		Wives of two gentlemen with disabilities.
n=2:	54	F	Inuit: I		
Community Members	34	M	Inuit: I/E		Interpreter & Outfitter
n=7	49	M	Non-Inuit: E		Nurse
	51	M	Non-Inuit: E		Social Worker
	42	F	Inuit: I/E		Former Homecare Worker
	34	F	Inuit: I/E		Interpretive Centre
	30	F	Inuit: I/E		Unknown
	52	F	Inuit: I		Unknown
Pond Inlet	62	M	Inuit: I	Peripheral Myopathy	
	79	M	Inuit: I	Respiratory Impairment	
	66	M	Non-Inuit: E	Stroke	
	56	F	Inuit: I	Osteoarthritis	
PWD	28	F	Inuit: I/E	Neurological Impairment	
n=5					
Caregivers	69		Inuit: I/E		Homecare Worker
n=3	53		Inuit: I/E		Homecare Co-ordinator
	29		Inuit: I/E		Mother of disabled child
Community Members	43	M	Non-Inuit: E		Homecare Nurse
n=2	42	F	Non-Inuit: E		Nurse in Charge (NIC)

Three participants with disabilities participated in Pangnirtung; one female and two males. The average age was sixty-six and the median was fifty-eight. All participants were Inuit and unilingual Inuktitut speakers. Seven community members took part; three male and four female. Two non-Inuit English speaking health professionals were interviewed and five Inuit who were active in local politics took part in the focus groups. The average age of community members was thirty-nine and the mean age was forty-nine. Two middle aged female caregivers took part, one in an interview, another in a focus group.

Five people with disabilities took part in Pond Inlet: three men and two women. The average age was fifty-eight and the median was sixty-two. The oldest person was seventy-nine and the youngest person was twenty-seven. One English-speaking non-Inuit person participated and four unilingual Inuktitut speaking Inuit took part. The youngest Inuit participant spoke Inuktitut and English and took-part in an interview. The three older Inuit participants took part in the focus group and the non-Inuit participant participated in an interview. Three female Inuit caregivers participated. One mother of a disabled child took part in an interview and spoke English and Inuktitut. The Inuk homecare co-ordinator took part in an interview. The other two participated in the focus group. One was a unilingual Inuktitut speaker and the other was bilingual. Two non-Inuit English speaking health professionals participated; one male and one female.

3.4 Data Collection

3.4.1 Overview

The majority of data was collected through five focus group sessions and sixteen semi-structured interviews held in Iqaluit, Pangnirtung and Pond Inlet over a six-month period of time. Analysis of this data provided the basis for describing facilitators and barriers to community participation (Chapter 5 & 6) and suggestions for future action (Chapter 7). Photographs, observations of physical community characteristics, documents from local interpretive centres and researcher participation in community functions provided a broader context for descriptions found in community profiles (Chapter 4). Four skilled Inuktitut/English speaking interpreters from Iqaluit, Pangnirtung and Pond Inlet respectively provided paid translation services.

3.4.2 Focus Groups

Focus groups are not a traditional data collection method used in ethnography. However, it was felt that focus groups would enhance the degree of participation in the project and bring people together to share concerns. The interaction among participants in focus groups is a valuable way of accessing data that would not emerge if other methods were used (Webb & Kevern, 2001). It allows people to explore and clarify their views. Furthermore, Kruger states that . . . "the permissive group environment gives individuals license to divulge emotions that often do not emerge in other forms of questioning"(Kruger, 1988, p. 230). Although not intended to be educational or therapeutic, exploring and clarifying views has also been reported to be an empowering aspect of focus group interactions (Brown, 1999).

Pilot Focus Group

A pilot focus group was held in Iqaluit on November 14th, 2002. Four caregivers took part and an interpreter provided cultural feedback on this session. Analysis of the focus group questions, transcript, participant interactions and the researchers' ability to moderate took place during and after the focus group. Kruger (1988) recommends this type of analysis. Minor modifications were made based on transcript analysis, evaluation of moderators performance, flow of session, and adherence to research objectives. The transcript was used in later analysis. This information was also used to create questions for interviews with community members and Inuit with disabilities.

In this pilot focus group, participants were asked to collectively draw the activities involved in a land journey. The goal was to understand facilitators and barriers that occurred during this type of participation. A diagram of an igloo separated into five chunks was used to represent the important components of life. Similarly diagrams of fish and nets were used to denote facilitators and barriers to participation. People wrote or drew inside these diagrams.

After analysis of the focus group session it was determined that participants were more comfortable telling stories to each other than writing or drawing. Visual cues were subsequently minimized and the igloo diagram was only used as a point of reference. Questions about health center roles were eliminated as this was associated only with illness and a greater emphasis on descriptions of participation was included in subsequent groups.

Focus Groups

Five focus groups were held at Community Health Centres, at the Iqaluit Public Health Building and at the Arctic College in Pangnirtung (Table 5). Four out of five groups

contained 4-7 people. This number has been described as an optimal number for interaction and dynamics of the group (Brown, 1999) Focus groups were 1.5-2 hours in length with one fifteen-minute break. Refreshments were provided and when possible, country food [7] was offered. Local interpreters were present for all focus groups. There was only one focus group held in Pond Inlet due to time constraints.

Table 5: Summary of focus groups: dates and participants.

Community/Focus Group	Date	Participant Category
Iqaluit		**8 Inuit Participants/1 non-Inuit**
Focus Group I (Pilot)	Nov. 14, 2002	4 Caregivers
Focus Group II	Nov. 25, 2002	5 Women with Disabilities
Pangnirtung		**8 Inuit Participants**
Focus Group I	Dec. 14, 2002	3 Community Members
Focus Group II	March 1, 2003	2 People with Disabilities 2 Community Members 1 Caregiver
Pond Inlet		**5 Inuit Participants**
Focus Group	Feb. 6, 2003	3 People with Disabilities 2 Caregivers

The primary researcher was the moderator of these focus group sessions. Frequently the researcher had a minor role and allowed participants to explore subjects they felt were of great concern. In many ways the interpreters assisted as moderators. They helped with country food preparation, clarified cultural nuances by rephrasing questions and debriefed with the researcher after the sessions. A framework of open-ended questions was used to facilitate discussion (Appendix D).

[7] "Country food" is a term used in this region to describe food harvested from the land like seal, caribou, muk-tuk (whale blubber), and arctic char.

Translation

In three of the five groups a process of *alternating translation* took place (Esposito, 2001). The interpreter sat in close proximity to the participants and to the researcher. The researcher spoke to the interpreter in English, and the interpreter translated in Inuktitut to the group. In this way, the interpreter provided visible translation of emotion and non-verbal gestures. The second group in Pangnirtung started with *simultaneous translation.* In this method, the interpreter is more distant to the group and translates into a microphone. This is projected to participants through headphones in their native tongue. However, everyone present felt that the emotion was not being conferred this way so alternating translation was substituted for this method. The first focus group in Pangnirtung did not require translation.

Jotted field notes were taken by the researcher during focus group participant interaction in order to capture non-verbal gestures and record reflexive thinking re: hunches, trends and emergent patterns. Jotted notes were expanded to full field notes within twenty-four hours. An Inuktitut interpreter clarified cultural nuances and interpreted verbal dialogue simultaneously. All focus groups were audio taped, and transcribed verbatim by the primary researcher and entered into the NVIVO Software Program (Qualitative Software Research, 2003).

3.4.3 Semi-Structured Interviews

Interviewing is cohesive with Inuit oral tradition as respondents are asked to generate narratives of their experiences. This was facilitated using open-ended questions in a way that allowed respondents to address research objectives (Miller & Crabtree, 1999). Qualitative researchers are now associating this method of data-collection with ethnographic studies

(Fontana & Frey, 2000). The interview protocol for caregivers and community members is described in Appendix D.

Each interview was thirty to sixty minutes in length, starting with general background information about the individual and progressing to open ended questions associated with prompts and probes. Location was chosen by the respondent in order to preserve context and assure comfort. Most interviews took place in participants' residences, and work places. Two took place in restaurants and one took place in the researcher's transient fieldwork apartment.

The purpose of interviews with caregivers was to build rapport and initiate a story that reflected experiences about disablement within the Inuit culture. Interviews with health providers provided additional insight into facilitators and barriers in each respective community. One exception to the above protocol took place. The final interview of the study was with a historian who had lived in the region for twenty years. The purpose of this interview was to ensure that emerging impressions of similarities and differences between communities were accurate.

Four interviews took place with individuals who participated in focus group discussions; three people with disabilities in Iqaluit and one caregiver in Pond Inlet. During the focus group meeting the researcher invited participants to speak to her again in an interview at a later date. People who volunteered were interviewed. The remainder of interviewees were chosen by convenience and expressed desire to participate. All interviews with people with disabilities in Iqaluit were follow-ups to the focus group. These interviews confirmed and/or disconfirmed emerging perceptions of their experiences. Sixteen semi-structured interviews took place in the Baffin Region; seven people with disabilities, three caregivers and seven community members. Nine of the interviewees were Inuit and eight were non-Inuit.

Seven interviews were held in Iqaluit; three with non-Inuit community members and four with Inuit people with disabilities. An interpreter was required for two interviews in Iqaluit with Inuit women with disabilities. Alternating translation was used in these cases. Three interviews took place in Pangnirtung; one family interview with a disabled Inuk gentleman and his wife, and two with non-Inuit community members. Six interviews took place in Pond Inlet; two with non-Inuit community members, two with Inuit caregivers, and one with an Inuk woman with a disability. An interpreter was not required for the interviews in Pangnirtung and Pond Inlet. Eleven interviews were audiotaped, and transcribed verbatim by the researcher. In order to create a less formal atmosphere, field notes were used to record five interviews. This information was entered into Nvivo qualitative software.

3.4.4 Photographs, Documents and Community Observation.

This secondary source of data supplemented interviews and focus groups in outlining contextual information in community profiles located in chapter four. Photographs of buildings, community layout, and surrounding landscape provided valuable information for describing the physical environment in each community. Descriptions of thirty photographs were entered into a proxy Nvivo document that represented the digital picture file. Documents such as community advertisements, pamphlets and tourist information booklets also provided additional information about the communities. Information from these documents was referenced and entered into NVIVO software in a file described as "documents" for Iqaluit, Pangnirtung and Pond Inlet respectively.

Descriptive field notes were written daily in each community. The researcher observed the general surroundings, interacted with community members, and participated in events like elders' feasts and local hamlet meetings. The researcher also went to the local interpretive

centers and libraries in each community, and volunteered locally in Iqaluit. These field notes were a valuable method of triangulation and served to confirm and disconfirm emergent patterns. This descriptive information was also valuable in creating a profile of the community layout and physical environment.

3.5 Data Analysis

Strauss and Corbin's constant comparative method for data analysis in grounded theory was used to analyze transcripts, fieldnotes and descriptions of photographs and documents (Strauss & Corbin, 1990). This is a type of data analysis that reduces data into meaningful unit codes and synthesizes codes to show a link/relationship at increasingly higher levels of abstraction. Due to the compressed nature of this ethnography and to the focus on transcript data, grounded theory was used in order to ensure an accurate portrayal of participant descriptions.

The research questions were kept in mind during data analysis but did not preclude the discovery of new concepts and ideas (Miles and Huberman, 1994). Miles and Huberman suggest that general areas of interest are identified prior to the analysis but that specific categories and themes to be explored are *not* predetermined. NVIVO qualitative software was used to manage this large quantity of data. This program handles text records, and allows the researcher to create and edit documents internally (Qualiative Software Research, 2003).

An inductive process was used to open-code *all* text and break these chunks down into categories and sub-categories. Data were analysed by community starting with Pond Inlet. Figure 1 provides a brief example of this process in Pond Inlet. As categories emerged in Pond Inlet, an iterative process took place while coding data from the other communities. Comparisons, contrasts and linkages were drawn between communities. Finally, the entire

data set was broken down into the following categories in each community: Community Profiles, Participation, Formal Support, Informal Support, "Getting Around", Areas of Social Vulnerability and Future Recommendations.

Coding	Sub-Category	Category
Overcoming Barriers of Weather & Terrain Unique Care of Equipment Snow & Gravel as Barrier Steep, Slippery Terrain Heavy W/C Difficult to Maneuver Difficulty Getting Around-Weather Falling on Hills Blizzard Prevents Travel	Weather & Terrain	"Getting Around"
Getting Rides Saving $ for Skidoo Barrier to using Skidoo Existence of Taxis PWD getting around – skidoos Types of Transportation Unclear Directives Vehicle	Transportation	

Figure 1: Example of Data Analysis: Pond Inlet

The content of these categories underwent a more detailed comparative analysis for similarities and differences between communities. The final categorical analysis was placed into a theoretical Occupational Therapy framework for a more cohesive presentation of the results. For example, the category "Participation" was broken down into productivity and leisure. "Formal" and "Informal Support" were place in a section on the Social Environment. The "Getting Around" category was placed into a section on the Physical Environment and broken down into transportation, and the interaction of weather, accessibility and equipment.

3.6 Validity

The purpose of validity in qualitative research is to create research that is applicable, credible, applicable, consistent and neutral (Miles and Humberman, 1994; Guba & Lincoln, 1989). *Applicability* refers to the ability of this study to be applied to other contexts and settings (Guba and Lincoln, 1989). A thorough review of the literature on cross-cultural disablement and of aboriginal health allows this study to be placed in a larger context. *Credibility* refers to reporting the perspectives of informants as clearly and truthfully as possible (Guba and Lincoln, 1989).

Triangulation enhances credibility through the use of multiple investigators, multiple sources of data or multiple methods to confirm the emerging findings (Merriam, 1998; Schmoll, 1993). In this study, interviews, focus groups, photographs, documents and community observation constitute multiple methods and enhance validity. Another method of obtaining credibility is member checking. Member checking refers to taking interpretations back to group participants and asking them if the results are plausible (Merriam, 1998). During the process of analysis, letters and transcript summaries were sent to three participants in Pond Inlet to verify interpretations. Feedback was received from two participants. Three follow-up interviews in Iqaluit served as member-checks for the focus group interpretations.

An attempt to be *consistent* is another way of obtaining validity in qualitative research (Miles and Huberman, 1994). Peer examination and review of analyzed data for accuracy and feedback also increases validity. Midway through the fieldwork process, the researcher met with two doctoral students of anthropology working in the North. A discussion about the first two focus groups took place. These two researchers emphasized the value of

empowerment through focus group meetings, emphasized the inclusion of inner dialogue, encouraged documentation of surprise events and suggested including photographs. An interim report was prepared for the researcher's academic advisor halfway through the fieldwork period. He reviewed the pilot focus group transcript and gave general feedback and direction for completion of the study. A qualitative researcher and faculty member at Queen's University reviewed and provided feedback on the coding of one section of a focus group transcript. In addition, a pilot focus group was held in Iqaluit to ensure that the protocol adequately addressed all research questions and was consistent throughout the study.

Neutrality is also important in a qualitative research study. Neutrality refers to the attempt to be free from bias, neutral and confirmable (Miles and Huberman, 1994). Reflexive journaling during the data-generating phase enhanced neutrality as it demonstrated the continuous process of critical analysis and exposition of bias (Mays & Pope, 2000). Reflective passages were written throughout the six-month fieldwork period. These notes described the researcher's interpretations of what was taking place, highlighted potential areas to explore and provided an outlet for the highly emotional fieldwork experience. In addition, the researcher acknowledges potential areas of bias that may occur due to previous experience in the region, her position as physiotherapist throughout the course of the study and to a Euro-Canadian frame of reference for Healthcare.

Chapter 4

Results - Baffin Region and Community Profiles

Chapter Four introduces the reader to the Baffin Region and to the communities of Iqaluit, Pangnirtung, and Pond Inlet. This chapter was created primarily from an analysis of fieldnotes, documents and photographs but also includes some relevant descriptions from focus groups and interviews. Regional similarities and community variations in the historical, geographical, socio-economic and cultural environments form the basis of a contextual comparison. These comparative descriptions also provide the foundation for describing facilitators and barriers to participation for people with disabilities in subsequent chapters. Features that distinguish Iqaluit, Pangnirtung and Pond Inlet provide insight into the unique contexts that exist in the Baffin Region for people with disabilities.

4.1 Common Threads in the Baffin Region

Environment: Negotiating the Natural Environment

The natural environment is rugged and extremely cold with subtle variations between Iqaluit, Pangnirtung and Pond Inlet. Most buildings are high above the ground on stilts in order to avoid the permanently frozen ground. In each dwelling, water is delivered and sewage is pumped out. Building construction must be carefully planned to coincide with the annual sealift ship that brings building supplies. Adequate housing is an area of vulnerability and it is commonplace to see three generations of families living in one home.

Snowmobiles and Qamutiks [8], four wheelers, cars, and trucks are used to get around in the communities. Major Nunavut communities have taxis, and only Iqaluit has public

[8] "Qamutik" is a commonly used Inuktitut word for long wooden sled towed behind snowmobiles or dogsleds.

transportation. Travelling between communities is expensive and arduous. Air travel from Iqaluit to the out-lying communities can take anywhere from one hour to Pangnirtung or four hours to Pond Inlet and return airfares range from $350 to $1200. Air travel from Iqaluit to Ottawa takes 3.5 hours and costs approximately $1100.

Environment: Health and Social Systems

The healthcare system here is operated through the Government of Nunavut (GN) and is geared toward meeting the acute medical needs of residents living in the Region. The Baffin Regional Hospital is located in Iqaluit and provides care through physicians. Basic medical needs are met here and physicians are on hand. Registered nurses and visiting physicians also provide medical care in community health centres. This includes acute care, distribution of medication, monitoring of chronic diseases and referring patients to specialists in Iqaluit or Ottawa. Physiotherapy and Occupational therapy services are provided occasionally to the communities but are based primarily in Iqaluit. Residents must travel to Ottawa if an intensive course of rehabilitation therapy is required.

Homecare has recently received a large amount of funding from the federal government and this is evident in the recent expansion of services in Iqaluit and in the communities. Although this system exists universally across this region, knowledge and usage of these services vary from community to community. One area of social vulnerability is the high suicide rate. Suicide rates in Nunavut are the highest in Canada, and communities are greatly affected. The visibility of alcohol and drug abuse varies from community to community.

Cultural Environment: "Going out on the Land"

Although the economy is undergoing a swift transition from subsistence to wage-based livelihood, values associated with being "on the land" [9] are still high throughout the region and instil a strong sense of pride in those who hunt, fish and camp. Walking around the communities on Baffin Island one will see framed seal skins stretched in frames leaning against houses (Figure 2).

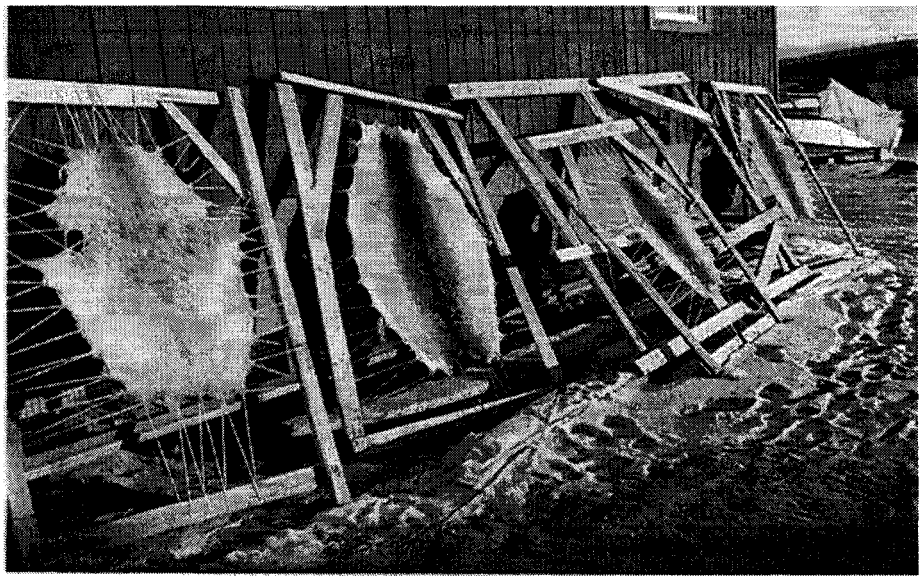

Figure 2: Photograph – Seal skins outside home in Pond Inlet.

This photograph gives a visual representation of the emphasis still placed on hunting. The majority of people have wage employment but frequently use money to buy snowmobiles, gas, guns and ammunition needed to go out the land. Values like independence, practicality and fortitude are rooted historically in survival and are strong in Inuit culture today. A statement made by a fifty year old Iqaluit historian reflects these values:

[9] The expression "on the land" is frequently used to describe being on the tundra or on the water. People travel out on the land by snowmobile, dog team or boat to camp, hunt, fish, seal, and collecting berries.

> I've seen people go out on wooden legs simply because that's just so important to people... people with heart conditions go out too because the idea of staying home... it just strips any sense of pride that you have away.

Conditions surrounding fishing, sealing, and hunting dominate conversations in the communities and even seeing animals and wild vegetable picking are important events for elders. For example, in Pangnirtung discussion focused on late arrival of the sea ice. This was inhibiting people's ability to hunt and subsequently creating a shortage of country food. A fifty-three year old homecare worker in Pond Inlet emphasized the value associated with traditional pursuits when she stated, "things like picking berries, looking at Narwhal and fishing make elders feel good".

Obtaining food from the land is frequently an unmet need in this region. Country food is now supplemented by store bought food and manufactured clothes have largely replaced skin clothing. However, the value attached to hunting, fishing, berry picking, and sewing is still pivotal to the social fabric of Baffin community life. Participation in this traditional means of subsistence is still inextricably linked with well-being:

> And, the other important thing to me is our minds. When the weather gets warmer we can go hunting and that is very good for our minds... one of the most important things to our lives. Going out gives us mental well-being.
>
> (51 year old Inuk caregiver)

Cultural Environment: Traditional Values & Beliefs

Raising children, providing for one's family and respecting elders historically provide a web of reciprocity within the Inuit community as each person fulfilled his/her role. One man may be delegated as the hunter for the family whereas another might earn money in the wage economy. Care giving of elders and people with disabilities has traditionally been the

woman's role but now, more women are employed outside the home and have less time available for this. A high value is placed on education that leads to wage employment.

The spirit of sharing with others is still evident, but is decreasing alongside the new emphasis on material goods. Where hunters might have generously given away fish to community members in the past, they often now sell fish or take part in inter-settlement trade.

4.2 Iqaluit Community Profile

Iqaluit (Figure 3) is located on the South Eastern tip of Baffin Island and is the capital city of Nunavut. Historically, Iqaluit was the site of a U.S. airbase during WWII and a radar site during the Cold War. As such Inuit have seen steady development occur here since this time. Iqaluit can be accessed from Montreal or Ottawa from the south, Rankin Inlet from the west and Nuuk, Greenland, internationally. Temperatures are the mildest of the Baffin Region communities but the annual snowfall here is greater.

Figure 3: Photograph - Central Iqaluit

The population of Iqaluit is expanding rapidly as it becomes more ethnically diverse. There is now an equal mix of 6000 Inuit, Francophone and Anglophone residents living here. The Inuit came from many different communities and a small percentage represent original inhabitants of this area. Iqaluit is changing rapidly and becoming a complex melting pot of people, values, and acceptable practices:

> The dynamics in Iqaluit have changed dramatically. The housing has dramatically increased ... it's hard to find people now. People say they live in house so and so that could be anywhere. In the past, you always knew where people were. So I think you can hide a lot easier in Iqaluit today than you used to.
>
> (50 year old non-Inuit community member)

Different worlds are evident in physical surroundings. An outdoor park contains massive stone carvings, Inuksuks [10] are visible on surrounding hills, and caribou skins can be seen outside local residences. These features, characteristic of Inuit culture, lie adjacent to fast food chains like Pizza Hut and Subway. Amidst a racquet club, swimming pool and movie theatre, an obviously dissimilar landscape emerges. There are three banks, three churches and a plethora of retail outlets in Iqaluit.

There are plentiful work opportunities in Iqaluit:

> From an economic standpoint there is a lot more jobs than they used to be. I think there is a sincere effort to try and get more Inuit into a lot of these jobs but I think there's no one has really dealt with the economic or the educational gap that still exists.
>
> (50 year old non-Inuit community member)

The Nunavut Legislative Assembly is located here, and many Inuit and non-Inuit work alongside each other in government departments. Other major sources of employment are utility corporations, retailers, vehicle dealerships, and restaurants. In contrast to prohibition

[10] "Inuksuk" is the commonly used Inuktitut word for a traditional Inuit stone configuration that resembles a person; Usually placed on the crests of hills and historically used for navigation on the land.

of alcohol in the communities, possession of alcohol is legal in Iqaluit by permit and many establishments here serve alcohol.

There are a large number of services available to residents, including the Baffin Regional Hospital, the Public Health Unit and the Iqaluit Homecare Service. Physiotherapy and Occupational Therapy Services are based in the Public Health Building. A centrally located Elders' Centre provides twenty-four hour care and a wheelchair accessible vehicle to transport residents to and from appointments. Iqaluit transit was in place as of March 2003 and now has two routes through town.

Volunteer organizations provide services through the Kamatsiaqtut Crisis Line and the Iqaluit Food Bank. A women's shelter is located in Apex, adjacent to Iqaluit. Organizations like the Qikiqtani Inuit Association (QIA), the Nunavut Government Department of Culture Language Elders and Youth (CLEY), and Nunavut Tungavik Inc. (NTI) are present here and dedicated to supporting Inuit economic, social and cultural well-being.

One participant suggested that people in Iqaluit go out less than in the communities yet stories of camping, hunting and fishing with family are still abundant. It is evident that some Iqaluigmiut [11] do place high value on land activities and get out frequently. An assessment of the degree to which Iqaluigmiut go out on the land and the value associated with this is beyond the scope of this study. Family is also very important to people here. Many participants described children, parents and elders as having a key role in their life.

[11] Iqaluigmiut is a commonly used Inuktitut phrase for "People who live in Iqaluit".

4.3 Pangnirtung Community Profile

With a population of 1276, Pangnirtung (Figure 4) is situated below an enormous Fiord in Cumberland Sound, Central Baffin Island. Pangnirtung is adjacent to the Auyuittuq National Park that encircles immense glaciers of the Penny Ice Cap (Figure 6). Despite the majesty of surrounding mountains and Fiords, the town itself has few steep hills. The wind here whips across the Fiord and frequently blocks air travel in and out of the community for days at a time. Iqaluit is accessible in less than one hour by air and the cost of return airfare is $ 350. This is the researcher's description of the flight into the community.

> The flight in was treacherous and frightening. The cross wind made the plane seem out of control as we banked across the Fiord. I'd forgotten how massive the mountains were, and how steep the fiord was that encapsulates Pangnirtung.
>
> (Researcher's Fieldnotes, Pangnirtung, Dec. 15, 2002)

Pangnirtung was the primary site of the whaling industry on Baffin Island from the mid 1800's to the early 1900's. Inuit and whalers worked alongside each other for many years hunting Bowhead whales and Kekerton Historic Park has been established in memory of the principle whaling station. The importance of their long history and intimate relationship with the Marine environment is evident as residents emotively describe their love of fishing char. Inuit in this area had an abrupt migration to the community in the mid 1960's when an epidemic swept through the dog population and government schools were established.

The economy in Pangnirtung is diverse. There is a government subsidized commercial turbot fishery, a National Park (Auyuittuq) and an internationally recognized arts and crafts centre (Uqqurmuit Centre). Auyuittuq National Park attracts a great deal of tourists to Pangnirtung and is a source of revenue for outfitters here. Newly decentralized Government of Nunavut (GN) departments also offer job opportunities for local residents. These jobs and

other local government positions in Health and Education exist in addition to service sector positions, such as those available in retail grocery stores.

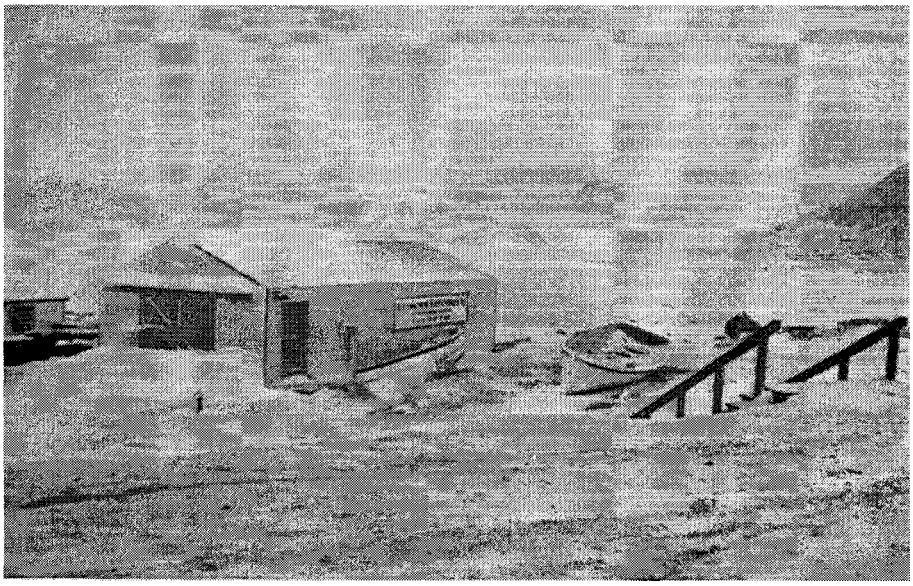

Figure 4: Photograph – Cumberland Sound and Hudson's Bay Trading Post

In Pangnirtung, there is a unique integration of western ideas into a traditional Inuit value system. Inuit here are assertive, self assured and proactive. People are knowledgeable about regional politics, and experienced in securing money for their community. They describe experiences in territorial organizations, and casually mention time spent in Iqaluit or Ottawa.

The line between men's roles and women's roles is not clearly delineated here. Although many women still sew frequently, they also participate independently in hunting and in the wage economy. Blurred gender roles are demonstrated by the comments of a thirty-four year old male Inuk community member. "Like years ago when women went fishing they always used to go with men but now, these ladies go, these guys will just go." This indicates that women go independently and separately. Notably, all homecare workers in Pangnirtung are men. The reason for this was not clear.

Despite these distinctions a great deal of importance is placed on maintenance of traditional values. The spiritual aspect of spending time on the land is frequently mentioned and participants spoke passionately about how hunting was good for their minds. Sharing is still integral to the fabric of community life and residents support one another in this way:

> That is a very old part of our culture that is still around today – sharing. When we were in smaller camps, we didn't lose our ways even though they moved into this big community. The more prosperous camps helped the poorer camps. The same thing is still happening today in Pangnirtung. The richer people help the poorer people.
>
> (58 year old Inuk woman with a disability)

The health centre here is quiet. Mention of alcohol and drug abuse is infrequent with only one situation surrounding alcohol abuse and one situation describing marijuana usage depicted. However, one suicide occurred during two fieldwork visits.

4.4 Pond Inlet Community Profile

Pond Inlet (Figure 5) is a remote community of 1220 people nestled along the Northeast Coast of Baffin Island. Icebergs separate the mountains on Bylot Island from the town on the mainland. Although this desert climate receives relatively low precipitation, the mean temperature in January is –35 degrees Celsius and blizzards can occur that last two to three days. The sun disappears in mid-November and does not re-appear until early February. The distance south to Iqaluit is 1062 kilometres and a return airfare is $1200. [12]

> My first impression of this community is of isolation. I knew there were mountains here but could not initially see them because it was overcast. Proximity to Davis Strait seems obvious. Three icebergs are set against what appears to be a very black arctic ocean.
>
> (Researcher's Fieldnotes, Oct.30, 2002).

[12] Temperatures and Distance from Iqaluit collected from Pond Inlet Document. Nattinnak Centre. Information for Visitors. Pond Inlet, Nunavut.

The community layout reflects mountainous surroundings with steep cliffs separating upper town from lower town. Numerous hills are present throughout the town. The RCMP detachment, Wildlife Office and Catholic Church are located on the beach in lower town. The community health centre, a new elementary school and the Anglican Church are on the ascent to upper town while the Toonoonik Sahonik Co-op and the Northern Store are housed on higher elevations in two opposite ends of upper town.

Other than a boom/bust period in the 1980's due to oil and gas exploration, the economy has favoured subsistence farming that includes sealing, fishing, and hunting caribou and whales. The Government of Nunavut (GN) has recently decentralized government departments to Pond Inlet in an attempt to provide more job opportunities for Inuit living in Pond Inlet. The schools and health centre are both funded by the Government of Nunvaut and provide a source of employment for local residents and a small number of non-Inuit people.

Figure 5: Photograph - Pond Inlet: Road leading from upper to lower town.

The Hamlet, retail stores and to a lesser extent, outfitting companies, are also components of the wage economy here. Sirmilik (North Baffin) National Park and the associated Nattinnak Interpretive Centre and Park Office have recently been established. Although tourism has not yet flourished, it is expected to be a source of economic revenue in the future.

Ninety-five percent of Pond Inlet residents are Inuit and five percent are non-Inuit. Inuk families still come here from North Baffin communities like Igloolik and Arctic Bay. Also, re-settlement from camps to Pond Inlet has recently taken place. Before the mid 1960's, most families lived on the land, coming into the community only to sell furs or buy supplies. The past two decades have seen the last Inuit move into town from the land. As such, memories of dogsledding, camp life, and risk of food scarcity are still vivid memories for adults and elders.

Male and female roles are clearly delineated here. In the community, men are conceptualized as belonging outdoors on the land, whereas women are frequently expected to be in caregiving roles. Notably, all homecare workers are women. A fifty six year old woman with osteoarthritis from Pond Inlet describes the importance of men going out:

> Men are more ... when they stay home they are worse than women. Cause men usually stay out more than women. Women usually just stay home. Men always go out. They are used to hunting and going out. When they can't go out it seems like it is worse for men.

The impact of alcohol and drug abuse was evident in Pond Inlet. One health provider passionately described substance abuse and violence as having a ... "huge, huge, huge impact across the board in our community". Situations were described in which drug use impacted the ability of a parent to secure food for his/her children, fostered a sense of helplessness in adolescents, and undermined the safety of elders. During two fieldwork trips to Pond Inlet,

one suicide and two drug overdoses took place. This statement encompasses the scope of the problem.

> One of her family members came back from jail and he was causing a lot of trouble. He wanted to use all of the money in the house for drugs. He was being very violent to everyone in the house and she was terrified of him.
>
> (43 year old female non-Inuit healthcare provider)

4.5 Chapter Summary

A harsh climate, remoteness from Southern communities, and existence of a rich Inuit culture based on an intimate connection to the land exist throughout the Baffin Region. Despite the presence of these regional characteristics, it is evident from community profiles that each community is unique. Differences exist in the social, economic, historical and geographical environments of these three communities.

Iqaluit seems to be the melting pot of the North with a heterogeneous blend of cultures. This town has experienced ample development over the last 50 years, and is losing its small community atmosphere. Iqaluit is the main centre for economic and political activity in Nunavut. In Pangnirtung, traditional values like sharing and inter-family reciprocity are highly visible but stereotypical gender roles are not as prevalent. The presence of a national park, a booming turbot fishery, and an acclaimed arts and crafts centre generate employment opportunities to residents living here. Pond Inlet appears to be a remote, traditional community with high value placed on land activities and traditional gender roles. Employment opportunities are more sparse and social vulnerabilities like suicide and abuse are more visible. Table 6 summarizes the characteristics of Iqaluit, Pangnirtung and Pond Inlet.

Table 6: Summary of Community Characteristics

	Geographic/Historical	Cultural	Social/Economic
Iqaluit	Capital city of Nunavut High snowfall Steady development since 1940's.	Mixed demographic Presence of organizations dedicated to Inuit Culture Value in traditional activities & employment.	Large number of job opportunities. Many available support services. Wage economy
Pangnirtung	Close proximity to Iqaluit Relationship with whalers & marine environment.	Integration western ways & traditional values Emphasis on community sharing. Connection between land and mental health. Overlap of men and women's roles.	Diverse and plentiful job opportunities. Low visibility alcohol/drug abuse. Wage >Subsistence economy.
Pond Inlet	Remote location Extreme cold Mountainous terrain	Recent Migration from Land Traditional delineation of men's and women's Roles Mix of families from North Baffin	Limited Job Opportunities Wage < Subsistence economy. High visibility of alcohol/drug abuse and suicide

Chapter 5

Results - Participation

Chapter Five describes the participation of Inuit with disabilities living in Iqaluit, Pangnirtung and Pond Inlet. For ease of organization, this information has been placed into categories that represent productivity and leisure (Townsend et al, 1997). *Leisure* will refer to those activities that connect participants to a broader context of social and cultural meanings in their communities. "Traditional Land Activities" will comprise the main sub-section of leisure. This reflects the emphasis placed on this subject in focus groups and interviews. *Productivity* will refer to an activity that contributes some service or commodity to others like the activities one might perform as a student, paid employee, volunteer, parent, or hobbyist.

5.1 Leisure

5.1.1 Traditional Land Activities

In Iqaluit, an elder with a disability fondly described one instance several years ago when her family took her out on the land. Her daughter stated how happy this trip made her mother and proceeded to describe events of the journey:

> We used a bigger boat because she is in a wheelchair. She's heavy, like two hundred pounds. It took four of us to put her from her wheelchair to the boat and ... that's how we did it. She was dressed warmly - and we took off. We went to where she grew up, where she was born in Inuqtung. In the tent, she has a special bed. It would have been too hard to transport her from wheelchair to the bed so she had a higher bed. We tried landing but there were hills everywhere, like rough rocks. We went to soft, flat sand. It was fun. We saw polar bears, caribou and we caught big, big fish. We just took her fishing there but she couldn't get out on the land so she stayed in the boat. We stayed in the boat.

This passionately narrated story illustrates the ingenuity, planning and fortitude necessary for an individual with a disability to get out on the land. Unfortunately this was the only

account of land participation described by participants with disabilities in Iqaluit. One worker from the Children's Group Home said she used to take some of the children out to pick berries. When probed further, it was clarified that only the children who could walk were taken out on the tundra. Several fond memories of camp life as children and young adults surfaced in Iqaluit. However, people with disabilities relayed few recent accounts of land participation.

The degree of participation in land activities in Pangnirtung was quite high. In fact, getting out on the land was part of everyday life for people with disabilities here. First and second hand accounts of this were abundant. In the focus group, community members started speaking simultaneously with three descriptions of various people with disabilities in the community going out. A health professional also commented on a family taking their young child with a disability on the land:

> And Andrea, coming in on a boat from having gone camping for several weeks with her foster family . . . so they would get her out. It's a lot of work to do it but they certainly did that.[13]

Descriptions from male participants with disabilities gave the impression of consistent seasonal outings, not isolated excursions. "I don't hunt in the winter-time, although I do in the summer time". The wife of an Inuit gentleman with a disability described getting out in the summer but noted the increasing level of difficulty doing so.

> We enjoy being outdoors especially when it's the season. Lately it's very difficult for me to transfer him alone without the appropriate help. Especially when they are out camping. We don't usually camp out too long. I'm not concerned about having people that do take us out. It's just that what would help me while we're there is a portable crank to lift him. If he doesn't go camping or out on the land it's hard because all his life it has been important.

[13] Psuedonym used here.

It appears that people with disabilities in Pangnirtung do get out but there seem to be restrictions based on season. Assistance will be explored in greater detail in Chapter 6.

People with disabilities who live in Pond Inlet went out less frequently. One ambulatory couple with disabilities stated that they went to their cabins from spring until fall every year, although this is becoming more difficult due to the necessity for portable Oxygen and a worsening medical condition. One gentleman with a disability spoke fondly of the days when he could go out on the land but had only been out once in the past two years:

> Sometimes I go out in the summertime. A couple of years ago I went down to the flow edge by dog team. Dog team is better because they're not as bumpy to ride on and they're not fast and dangerous. When the weather gets warmer I would want to go out more. But I won't be able. It's going to be hard for me.

A non-Inuit health professional commented that the same gentleman had not been out hunting for some time. One young woman with a disability reported not getting out on the land very often. However, she spoke enthusiastically about participating in a caribou and seal skinning session taught by elders' two years prior. A parent of a child with a disability tenderly described one occasion where she took her daughter on the land to pick berries, seal, and fish for char. Despite the emotive descriptions of time spent on the land in Pond Inlet, most of these descriptions were of past events. Recent, consistent participation in land activities rarely occurred.

5.1.2 Other Types of Leisure Participation

People with disabilities describe other types of leisure participation as well. Playing bingo, attending church and attending elder's functions like teas and feasts were important leisure activities in all communities but the degree that individuals participated in these activities varied.

In Iqaluit one non-Inuit participant described her desire to watch hockey games at the arena, movies at the theatre and attend classes at the pool. Furthermore one young woman described a desire to visit family but faced difficulty doing so. Barriers to these activities will be discussed in Chapter 6.

In Pangnirtung, family members visited one another frequently and informal contact occurred regularly in the community at hamlet meetings, craft sales, and elders' feasts. In Pond Inlet, people with disabilities state that they don't visit each other as much as they used to and don't get out very much in the community. However, participants described occasionally participating in elders' teas and one description was given of a disabled gentleman attending church on a Sunday. The following is an example of inability to go out in Pond Inlet.

> When I feel like going out somewhere I can't because I'm worried about my husband. My wish is that my husband could have someone to talk to. Cause, he never has any visitors. She wishes that there could be a male that her husband could talk to.
> (56 year old Inuk woman with a disability).

People with disabilities living in Iqaluit, Pond Inlet and Pangnirtung participate in traditional and non-traditional activities to varying degrees. Community and land activities occur regularly in Pangnirtung. To a lesser degree, camping occurs for people with disabilities in Pond Inlet, yet residents here feel they don't get out very much in the community. In Iqaluit, there wasn't a great deal of participation in leisure activities.

5.2 Productivity

5.2.1 Iqaluit

Despite the fact that women in Iqaluit with disabilities are not formally employed, there is still a great deal of discussion about this issue. One twenty-year old woman with a grade ten

education derives satisfaction from cooking traditional food and counselling friends. She is presently seeking employment and "wants to have something to do". She is having difficulty because of the necessity for bi-annual medical travel to Ottawa.

Another fifty year old Inuk woman who reported having a political science degree said she struggled to maintain employment after becoming severely disabled:

> I was an advocate between RCMP and Victim Services. I used to go to work with my wheelchair but then I had to quit. They kept the job open for three months but then I couldn't use my hand anymore. This one . . (pointing to right hand). But I didn't know then, I hadn't learned then about using a using a computer after being disabled.

Subsequently, this woman experienced success in her career as an artisan and is well known in this region for her ink drawings that portray her early camp life in Pond Inlet. Her ink drawings sell for approximately $150.

> I didn't know who I really was until I became a disabled person. I didn't know I have an amazing beautiful talent. I can draw as if I'm not disabled at all. You will know this when you see the pictures of my drawings.
>
> (50 year old woman with disability)

In Iqaluit one woman proudly displayed a bag of intricately embroidered slippers. She kept these in her bedroom and sold them informally to community members. Another forty-two year old non-Inuit woman didn't work because she was too "sick". This woman was concerned about what the future held for her two children as she was determined to send them to University. She cared for her daughters at home.

> I have two daughters and I live my life for my daughters. I don't work, I'm at home with my children and they're just young, they're very important to me and my idea is to get them into university when they're older. I don't know how I'm going to do that because I don't have a job.
>
> (42 year old non-Inuit woman with a disability)

5.2.2 Pangnirtung and Pond Inlet

One gentleman in Pangnirtung participates in political activism and has worked with the Nunavut Council for People with Disabilities in the past. Another elder is a revered, well-known, maker of kamiits [14] and stencilled print work. Another gentleman is retired from government service.

One young woman in Pond Inlet who possesses a certificate in early childhood education from the Arctic College recently quit her job at a local daycare due to lack of funds and is pursuing unemployment insurance. A non-Inuit gentleman in Pond Inlet is self-employed as an Internet service provider. Participants with disabilities in Pond Inlet reported few activities related to productivity. Table 7 describes activities of productivity by community.

Table 7: Activities related to Productivity by Community

Iqaluit	50 year old female	Artisan: Ink drawings
	59 year old female	Artisan: Sews & embroiders slippers
	46 year old female	Cares for children at home
	20 year old female	Cooking, counselling friends, looking for formal employment
	74 year old female	Elder: [activities not described]
Pangnirtung	78 year old female	Artisan: Well-known Kamiit maker, & artist
	62 year old male	Active in politics and regional committees.
	58 year old male	Retired from government service.
Pond Inlet	66 year old male	Self-employed: Internet business
	28 year old female	Recently unemployed from work as daycare instructor.
	56 year old female	Unemployed [activities not described]
	79 year old male	Unemployed [activities not described]
	62 year old male	Unemployed [activities not described]

[14] "Kamiit" is the Inuktitut word for seal skin Boots

5.3 Chapter Summary

Participation in activities related to leisure and productivity vary between Iqaluit, Pangnirtung and Pond Inlet. A discrepancy is apparent between Pangnirtung and the other communities. People with disabilities go out on the land the most in Pangnirtung and to a lesser extent in Pond Inlet and Iqaluit. Although people in Pond Inlet and Iqaluit speak fondly of time spent on the land, these trips are infrequent and seem to be compounded by many factors. Participation in other leisure activities appears to occur more consistently in Pangnirtung as well.

Twelve out of thirteen individuals with disabilities did not take part in full time paid employment. Many were productive, however in individual pursuits like art, cooking and political advocacy. Productivity is an important part of life in Iqaluit. With one exception in Pond Inlet, women in Iqaluit pursue individual activities more readily and place greater emphasis on paid employment. Participation in other productive activities also occurs most readily in Pangnirtung.

The activities of leisure and productivity described above are facilitated or hindered by a host of environmental factors within the social and physical environments of these three Baffin Island communities. An examination of these factors in Chapter 6 may offer insight into the varying degrees of participation experienced by people with disabilities.

Chapter 6

Results:
Facilitators and Barriers to Community Participation.

6.1 Introduction

This chapter is based on the analysis of focus group and interview data. Factors in the social and physical environments of Iqaluit, Pangnitung and Pond Inlet as they relate to disability will be compared and contrasted through rich descriptions and liberal use of quotations. Please note that gender is not ascribed to quotations from caregivers as all caregivers in the study were women. The *Social Environment* has been described under four section headings.

- Community Knowledge and Attitudes toward disablement
- Formal Support
- Informal Support
- Areas of Social Vulnerability.

The *Physical Environment* has been described under two section headings.

- Weather, Accessibility and Equipment
- Transportation.

As the reader will see, facilitators and barriers are present throughout. However, an examination of the similarities and differences in the social and physical environment of these communities begins to offer insight into *why* participation for Inuit with disabilities varies between communities.

6.2 Social Environment

6.2.1. Community Knowledge and Attitudes toward Disablement.

Iqaluit

Perception of historical Inuit attitudes toward people with disabilities set the stage for describing present knowledge and attitudes in this community. Three historical accounts of disability indicate negative attitudes existed in the past toward individuals with disabilities. The first depicts people with disabilities as the victims of ostracism or death:

> When family gets too much, or the parents do not wish to keep their own kid who has a disability, they abuse them physically and mentally. Sometimes long before 1930's, they used to leave them or kill them either with a rock. Beating them in their head or knife them to bleed to death . . . it is not like this any more.
>
> (50 year old Inuk woman with a disability)

Later, people with disabilities were still seen as unfit partners.

> Her husband, he had a stroke. No, he had operation in the head. Half of his face lost muscles and an adult asked her if he would still be her husband.
>
> (52 year old Inuk caregiver)

> It used to be worse, years ago. My mom was disabled ever since she grew up with bad arthritis. When she and my father got together, people didn't like her because she was disabled. 'Always sick', they'd say. You should die so your father would have a better wife. That was years ago but it still hurts. (37 year old Inuk caregiver)

It is important to consider this seemingly negative perception of people with physical disabilities in the context of cultural values at that time, when physical aptitude was necessary for survival. Now, many participants have experience with health providers in the South[15] and there is a general awareness of accessibility needs. Knowledge of advocacy groups like the former Nunavut Council for People with Disabilities was also evident in discussion. Disappointment was voiced at the lack of outcome from a recent meeting in

[15] Southern or "South" is a colloquial term used by Northern residents. It refers to cities accessible to the South by air, mainly but not exclusively Ottawa or Toronto.

Iqaluit where issues for people with disabilities were discussed but no tangible outcome was seen.

> They just talk. There was a big meeting in May. We had a big meeting with disability and they didn't do nothing. They said they were going to do lots of things that we talked about. Accessible stuff. Never, never. (50 year old Inuk woman with a disability)

One woman described a similar sentiment and relayed her experience attempting to get in touch with a disability representative in Rankin Inlet.

> There is a person that's designated for disability complaints and one time maybe a couple of years ago they had this big meeting in Rankin. This man said, 'nobody ever calls me about it, there's no complaints about disability'. So they gave out the number and I called and I got an answering machine and I never got a return phone call . . . . .
> (44 year old non-Inuit woman with a disability)

Attitudes toward people with disabilities were emotively described. Negative stereotypes and misunderstanding within the community make it difficult for people with disabilities to really feel a sense of belonging. One woman felt strongly that cognitive impairment was incorrectly associated with physical limitation. Many phrases emerged from different focus group participants describing how community members may perceive people with disabilities:

- When I was physically normal I was not told all of that negative stuff I receive today.
- You feel like you are being treated as a different person.
- Some people treat people with disabilities as if they are not part of us . . . of society.
- Sometimes we don't say anything because we get so hurt when people mistreat people with disabilities. Even right in public places when they don't understand.
- You're not invited anymore because people think you are too sick, you have to stay home.

(Iqaluit: Focus Group Participants)

These perceptions give participants a sense of isolation and loneliness. Women appeared to feel empowered by expressing these feelings of anger and pain. At an individual level,

people were able to convey how their true selves emerged through inner struggle and how those struggles continue each day. One young woman with a disability was passionate about her inner conflict and development of strength:

> It doesn't make any difference if I try to make something out of what I have. I just keep up with myself as much as I can. The more I put myself down the more it's going to get worse.
> Iqaluit: Focus Group II

> She talked about seeing herself as outspoken and couldn't help but smile at the thought that people have told her she should be a motivational speaker. She reported doing a lot of counselling. She feels that having a strong mind is important and sees her as having talent, and something to offer.
> Iqaluit: Interview fieldnotes, Feb. 25., 2003

(20 year old Inuk woman with a disability)

Despite exposure to healthcare systems, and Southern views of disablement, participants with disabilities feel that the attitude and level of knowledge present in Iqaluit is low. Furthermore, stories of how people with disabilities were treated in the past may still have an impact on the present level of awareness and acceptance within the community.

Pangnirtung

In Pangnirtung, detailed descriptions of mobility items seen in the South like scooters, walkers, and accessible vans confirm that residents are cognizant of equipment needs. Furthermore, an explanation of how these items may be useful in Pangnirtung indicates a knowledge and attention to disability needs. Participants are aware of specialist services in the South and of the role of Physiotherapy in relieving pain and assisting with exercises. One sixty-two year old gentleman with post-polio syndrome has been the chairperson of Nunavut Territorial Council for People with disabilities, is an accessibility advocate within the

community and has liased with NTI territorially. He described the presence of funding for disability related needs but expressed uncertainty regarding its' use.

> NTI has set aside $100 000 slated toward handicapped people and Joseph's group can use that money at their discretion but it hasn't been finalized yet. They haven't decided how to use it yet. Like there's no frame of reference yet on how that money can be accessed.

Pangnirtung participants' continuously describe people with physical disabilities as being an integral part of the community. Physical limitation is downplayed and they were described as being just like everybody else. The following three quotations reflect this attitude:

> With Joseph and Simon they seem to belong but . . . they do belong like they are part of our community. They just don't walk that's the only difference.
>
> (34 year old male Inuk community member)

> You know, they became very used to having Rachel in the class and she was just another class member . . . I'm not sure you'd find that in a lot of places that were this isolated.
>
> (51 year old male non-Inuit health professional)

> Their minds are not affected by their disability so they're able and she's happy you are here. Sometimes they're even wiser than us. The only difference is that we have a little more physical ability than them.
>
> (51 year old Inuk caregiver)

Descriptions of the integration of a child with a disability into the school system is described by two health professionals as a contributing factor to positive attitudes. Another contributing factor may be the fabric of the community itself as comparisons were made to other communities that did harbour poor attitudes toward people with disabilities. The second focus group in Pangnirtung felt that a committee specifically devoted to the needs of people with disabilities would benefit the community and be crucial to addressing the future needs of individuals with disabilities.

Pond Inlet

In Pond Inlet there is an air of perseverance and determination amongst people with disabilities. A sixty-two year old elder downplayed his disability: "My problem is my legs are weak. That's the only problem." He has been seen in the community walking over steep hills and snowdrifts with his walker. A forty-three year old health professional describes how she reflected on her own behaviour after an elder became offended at an offer of assistance:

> There is a great sense of pride in people and I think that really strikes me. Going into people's homes and you know they don't want to be condescended to. There's a great sense of pride and 'yeah well, you know I might fall down but I've been doing this more than you have probably' so [laughing] that's where it came from I guess.

A strong association between physical mobility and mental wellness in Pond Inlet may be at the root of this observation. A statement by a fifty-six year old Inuk woman with a disability describes words of her father that place significance on the mind body connection: "When they can't do anything anymore they start to worry a lot. When their bodies stop, their minds just won't work."

Knowledge and awareness about disability in Pond Inlet is not highly visible. Two health providers interviewed in Pond Inlet were aware of Southern healthcare systems and accessibility methods. Descriptions were given of systems in which respiratory equipment was readily available, and organized programs were present that takes elders grocery shopping. Inuit participants gave few descriptions of Southern experiences. This reveals that there may be different perspective between Inuit and non-Inuit with regard to disability related needs.

One young Inuk woman with a disability stated that she ... "didn't really trust them here". This was based on the reception she received from community members in Pond Inlet after

moving from another North Baffin community. She said people inquire about her condition frequently which ends up hurting her feelings. A young mother of a child with a disability stated that she had received a "so-so" response from the community and had heard mean words about her disabled daughter. Similarly, another healthcare provider said that she would ..."like to think there was more community support than what you actually see". She felt that there was little community support for people with disabilities in Pond Inlet.

The only visible signs of awareness and knowledge about disability came from a discussion that occurred at the Pond Inlet Community Hamlet meeting. The construction of a long-term care facility that would provide a safe environment for elders was a primary concern. The terms "accessibility" and "disabled people" were used in this meeting.

Summary: Community Knowledge and Attitudes toward Disablement

Knowledge of healthcare services, medical interventions and Southern methods of improving accessibility are evident in Pangnirtung and Iqaluit. Despite this awareness, participants in Iqaluit express concern over attitudinal barriers within the community. Subsequently, it has been difficult for them to create a unified voice to express concerns. This has left participants here feeling somewhat ostracized from society.

The presence of knowledge and positive attitudes are facilitators to participation in Pangnirtung. People here appear to have knowledge of Southern systems, and foster an inclusive, integrative attitude toward individuals with disabilities in their community. Pond Inlet has a low level of exposure to Southern systems and methods of improving accessibility. There is an obvious gap in knowledge about disability amongst caregivers and people with disabilities in Pond Inlet. Furthermore, the community doesn't appear to rally around those that need assistance with the same vigour seen in Pangnitung.

6.2.2 Formal Support Systems

Homecare: Iqaluit

Many changes have occurred in all three communities due to an influx of federal funding into the Nunavut Homecare Program. Pond Inlet and Pangnirtung now have a nurse who is in charge of running the homecare program. The Iqaluit Homecare Program has four nurses and four support staff. Training has taken place for homecare workers over the past year. A staged system is in place, Homecare Worker I and Homecare Worker II, where new skills build on previous ones. Transfers, bed mobility, respiratory therapy, and basic nursing skills like hygiene and wound care are taught to homecare workers infrequently in one-week community based courses.

The Iqaluit Homecare Program liaises closely with the Baffin Regional Hospital. The goal is earlier discharges from the hospital into the community. As such, distribution of medications, oxygen therapy supervision, and blood work co-ordination are key roles. Basic equipment needs are also addressed. Support is provided to new mothers and more recently to pediatric clients. Homecare workers describe duties like bathing, dressing, and visiting with clients. Only one homecare worker described performing exercises as part of her job and all workers who participated expressed concern over lack of training.

Three female participants with disabilities commented on homecare. One elderly participant simply stated she was thankful for her homecare worker. Another received homecare in the past to assist with housekeeping duties. A non-Inuit participant stated that she received help in Rankin Inlet with housekeeping duties but did not receive this type of help in Iqaluit.

Homecare: Pangnirtung

Family play a significant role in providing basic support to people with disabilities in Pangnirtung, but the role that home-care plays is seen as equally important. A male community member comments on the utility of homecare: "It seems to be working well now with the home-care program. These guys are working now. In the past it used to be all family and now it's really helpful."

However, two specific examples of inconsistent attendance of homecare workers were of concern to participants. A woman who was the sole caregiver for her disabled husband also expressed concern over not receiving financial compensation for her role as caregiver in her household. In the focus group she was described as ... "the homecare worker" for her husband. Other focus group participants reiterated this concern. They felt that having to leave the house for wage employment while a home-care worker was paid to care for a loved one contradicted the spirit of family togetherness. A male non-Inuit health provider felt that the new presence of a nurse who could devote all of his/her time to the homecare program would enhance the capacity for supervised rehabilitation programs.

Homecare: Pond Inlet

In Pond Inlet, the new home-care nurse feels that this program has had a positive impact. He is interested in rehabilitative programs and organized an in-service course for homecare workers on transfers, bed mobility and exercise during a fieldwork visit. Requests for assistance with land participation from clients demonstrate that this resource is being utilized. There is, however, some resistance to full acceptance and integration of this program into the

community. A fifty-three year old caregiver conveys this concern: "Some homecare clients don't understand what the homecare nurse is trying to do. They think he is not a real nurse and are not happy to see him sometimes." In the past, homecare has focused predominantly on housekeeping services. Homecare workers stressed that people with disabilities just needed someone to talk to.

Healthcare: Iqaluit

A fifty-year old woman with a disability in Iqaluit describes the Healthcare System. She writes about supports present within this system but indicates that people with disabilities are still being neglected as greater emphasis is placed on illnesses and accidents that take up valuable medical resources. Her sentiments, described below, echo those of the regional nutritionist who feels that immediate crisis management over-shadows dedication to long-term planning for community wellness.

> Disabled people are being neglected. The Iqaluit Town Council has a social worker but disabled people say they never get any help from them. Doctors bring people who are very needy or disabled to the hospital or public health centre to be checked out. They can only take emergency patients. That is why disabled people and elderly are dying quickly. Their support systems are being cut off. They have people who go on home visits and help disabled persons. There is only one therapist who helps out all kinds of disabled peoples in Baffin Island. (50 year old Inuk woman with a disability)

Despite the expressed shortcomings in healthcare, there was an emphasis by participants on the importance of doctors and healthcare providers in assisting them to function. Medications were the main reason for improved function. One exception to this came when a participant described feeling distrust and anger toward an Ottawa health professional. She travels there every three months to receive painful anti-spasm injections. Incessant visits to Ottawa for specialist visits leave her feeling frustrated and preclude her from finding stable employment in Iqaluit. Overall, healthcare workers and doctors were portrayed positively.

Healthcare: Pangnirtung

In Pangnirtung, several deficiencies were noted in the healthcare system. Most noted was the inability of the health centre to cope with rehabilitation concerns. Focus group participants gave three examples where rehabilitation needs in the area of equipment, service, or homecare were not met.

When asked about barriers to participation during the second focus group in Pangnirtung, a group discussion about the need for a physiotherapist ensued. An elder with osteoarthritis stated her concerns. "We really need to have a physiotherapist and a place to have that done. But the nurses say, nah, you're all right. It's been a while since they've asked me to come for physiotherapy." Another community member also stated the need for a physiotherapist.

According to a non-Inuit health provider, the expectations of nurses at the Pangnirtung Health Centre far exceed their capacity. Nurses are seen as the sole access point to other specialty services like physiotherapy and occupational therapy. As such, responsibility for short and long term rehabilitation follow-up are placed with them. Limited expertise, and overwhelming acute care and public health needs leave nurses with little available time to devote to rehabilitation issues for people with disabilities in Pangnirtung.

Healthcare: Pond Inlet

Facilitators and barriers within the healthcare system were rarely referred to in Pond Inlet. A fifty-year old health professional stated that although individuals with chronic disease and disabilities are seen on a regular basis, the majority of health centre activity revolves around clients with acute needs.

A young woman who cares for her disabled daughter is moving her entire family to Ottawa to be close to her doctors there. She describes the reasons preventing her from doing this earlier:

> I have lots of relatives here and I have to keep in contact with them. Plus I also wanted her to let my children know they have other relatives here. But now it's time that we moved down there... to be close to her doctors.
>
> (30 year old Inuk caregiver)

Another twenty-eight year old woman with a disability travels frequently to Iqaluit for medical appointments and describes using the Health Centre only for refilling prescriptions. When the issue arose of people having someone to talk to, one caregiver said people with disabilities had to wait months, even years before the system provided a social worker.

The stress of travel to receive services, focus on acute care, and delay in receipt of social work service gives the impression of limited resources in Pond Inlet. However, the need for health services was not strongly expressed by participants here. The need for rehabilitation service provision was not mentioned.

Summary Formal Support

Homecare embraces the medical model of health more visibly in Iqaluit. The program provides support to the medical community, and is valued by participants for assisting with bathing and dressing and providing transportation to and from medical appointments. Despite the support offered through homecare there participants still believe that people with disabilities are being neglected by the healthcare system due to more acute priorities.

Residents of Pangnirtung feel that homecare is valuable but have suggestions for improvement. A need is expressed here for greater rehabilitation service as this appears to be beyond the capacity of the health centre. Prior to 2002, there was not a full-time nurse

working for the homecare system in Pond Inlet. People here are adjusting but in some cases may be reticent to embrace an outsider coming into their homes. Needs in the area of rehabilitation did not surface in this community. Homecare appears to facilitate participation for most individuals in these three communities. Community members and caregivers feel it assists people who do not have family support.

6.2.3 Informal Support

Family Support: Iqaluit

As described previously, family is an important part of the value system in Iqaluit. However, this importance does not parallel the amount of support people with disabilities receive from immediate and extended family members. Six examples were given in which family members facilitated participation. Four of these examples, however, came from one family. In this family, a seventy-four year old elder with congenital right arm dysfunction and history of stroke was assisted with land activities, attending church, and daily living. Her family was strong and numerous.

On the other hand, seven statements from different participants describe lack of family as a barrier to participation. This normative depiction uses these statements to present a brief cultural representation of the situation that exists when there is lack of family support in Iqaluit (Lecompte & Schensul, 1999).

> I come from Arctic Bay. I moved to Iqaluit and I don't have much family here. I use a wheelchair to get around because my legs are weak. My kids and my grand kids help but it's hard. They all live with me and some of them are busy working now. They expect me to do the cleaning but sometimes I can't. It's hard . . . but I don't want to say anything. I would like to have someone to depend on so I could get out more.

Family Support: Pangnirtung

Family was described as a support to people with disabilities in Pangnirtung. Inuit and non-Inuit community members, caregivers and people with disabilities gave seven examples of support in daily activities and participation in land activities. A forty-nine year old non-Inuit health provider in Pangnirtung speaks openly about the support provided by families in Pangnirtung and compares this to his experience in the South.

> The families here are pretty close so anybody who lives with disabilities has a lot of family around them to provide support. So we don't really have it like you would in the South where most wheelchair bound people are stuck by themselves in their little apartments and completely isolated from any kind of community help.

In contrast to the norm, one example was given of an individual in the community who is a paraplegic. His parents are dead, he does not like to go out, and he rarely has visitors. He uses marijuana and is attempting to get this legalized for himself. A fifty year old social worker with twenty years of northern experience states that although the support is presently in tact from family, most caregivers are in their forties and fifties and with a degradation of family values and change in work ethic there may be differing support in the future for people with disabilities. Two caregivers did express that, although they were the primary support for their loved ones, there was a strong need for additional assistance. The following is an example of this sentiment:

> He used to have community living workers but we don't have them anymore and I do most of the work. I have two daughters living with me but they are both busy; one working and the other attending college. We don't want a community living worker because they always tend to quit or be transferred somewhere else. I need to be here and help him because I know he has a disability. Sometimes I get tired too.
>
> (54 year old Inuk caregiver)

Family Support: Pond Inlet

Viewpoints differed in Pond Inlet about family roles in providing support for people with disabilities. One gentleman commented that his children usually took him places but were not always available to do so. Although she said that her children help, a fifty-six year old Inuk woman with osteoarthritis noted the low level of assistance she received from her children.

> My problem is that I can't lift heavy things and my husband can't. I ask my children, they won't do it. Nowadays they're not like they used to be. Because before they would always do things for their parents now they are lazier and they don't do things as much for their parents. Kids help sometimes when they're not lazy.

Furthermore, women here feel that there is an expectation for them to be the carers in the community. Healthcare providers believe that family has a big role in support but it is unclear whether that expectation is met. One thirty year old participant and mother of a disabled child is moving to Ottawa because finding people to care for her other children during medical visits South is too hard. Her sisters help her sometimes but they are all employed and busy.

The issue of safety from abusive family members was raised on three occasions. One male health professional commented on the gravity of this issue. He stated that . . . "sometimes the elderly are afraid of their children but they're stuck so the kids just come in and things are stolen and you know it's just a really bad situation". One young disabled woman is estranged from her family who live in Pond Inlet. She speaks to her mother once a year and receives little emotional support from her family.

Community Support: Iqaluit

Informal demonstrations of support for people with disabilities in Iqaluit are rare. One fifty-eight year old woman with post-polio syndrome said that "Polar Man" shovelled her ramp. Polar man is a well-known young man with a personality disorder who believes he is a

super hero and randomly assists people in need. Another case of informal community support occurred when a welder volunteered to fix a broken foot brace for a young man with a disability. These two instances were the only random shows of support depicted by people with disabilities. One resident has seen many changes occur in Iqaluit and comments on how this may impact people with disabilities:

> I think you can hide a lot easier in Iqaluit today than you used to. And that has been bad I mean, from a negative standpoint there may be people having some major problems and they just don't get noticed. (50 year old male non-Inuit community member)

Community Support: Pangnirtung

Community members in Pangnirtung are aware of people's needs and take action to mitigate difficult situations for people with disabilities. Examples were given by six different participants of occasions when informal support was demonstrated within the community. Phrases like "there's a great deal of compassion", "in the community we are helped a great deal", and "people with disabilities are helped so well", exemplify the presence of an inclusive community spirit. Shopping, carrying groceries, laundering clothes, providing assistance with walkers in deep snow and helping people get from one place to another are examples of the type of informal support provided within Pangnirtung. Action versus inaction by community members is pervasive in discussion:

> We don't just look if someone needs help. Everybody goes out. Like, we don't have to carry groceries or anything that needs to be carried. People help us all the time.

Community Support: Pond Inlet

People with disabilities in Pond Inlet gave two examples of informal community support. One young woman said that people stop now and ask her if she wants a ride to work. Another sixty-six year old non-Inuit gentleman described calling the grocery store and having

cigarettes delivered by a friend there. He also described a situation in which he called a community member for help during a blizzard and was subsequently rescued.

Summary Informal Support

Family facilitate participation to the greatest degree in Pangnirtung and to a lesser degree in the other two communities. In Pangnirtung, family here is seen as a considerable support to traditional land participation and daily living for people with disabilities. Informal support from community members seems automatic and integral to the social fabric of Pangnirtung. Evidently, absence of informal support from community members is a barrier to participation in Pond Inlet and in Iqaluit. There appears to be conflicting family roles amidst an indifferent attitude and inconsistent shows of support from community members in Pond Inlet. People in Iqaluit appear to be well hidden in a town with a larger population and geographic layout. The presence of informal support in Pangnirtung and absence of informal support in Pond Inlet requires further interpretation (Chapter 8). Absence of family may be a universal barrier to participation in all three communities.

6.2.4 Social Vulnerabilities

Iqaluit

In Iqaluit, two participants with disabilities openly spoke about suicide. This initial confession and response to it in one of the focus groups demonstrates the impact suicide may have on individuals with disabilities.

> I've got to take care of myself to take care of my children and I feel, especially when I first got sick, I got so sick I couldn't change my babies diaper, I couldn't pull the thing down, the tabs off and if I didn't have children I would have died. I would. Not because I would give up but because I would have taken my own life because it was that painful.
>
> (46 year old non-Inuit woman with a disability)

> I really feel like I could start crying right now because it brings me back to when I started to have, when I was there. I almost killed myself with sleeping pills because I was so, ... like she was. Her life story is about my life story.
>
> (50 year old Inuk woman with a disability)

Inadequate housing was an issue for two individuals with disabilities. One fifty-nine year old woman with post-polio syndrome lives in a small cramped two-bedroom house with six occupants. This house has holes in the walls, poor air quality and an inaccessible bathroom. Consequently, this woman experiences occasional nose-bleeds. She uses her upper body to hoist herself in and out of the bathroom. Similarly, another wheelchair user stated that proper housing was a big concern for her. She also had problems getting into and out of a high bathtub independently. Two observations were made about poverty and food security. Many individuals with disabilities used the food-bank, and leftover country food from the focus group was frantically packaged and taken home.

Pangnirtung

> It was evident that suicide also has an impact on people with disabilities in Pangnirtung.
>
> John took me aside and gravely reported that there had been a suicide in the community over the lunch hour. Later that day I received a phone call to explain that Ineak and Ina would not be attending the focus group because their daughter's boyfriend had been the one who committed suicide. [16]
>
> (Researcher's fieldnotes, Feb. 28., 2003)

Contrary to the problems with food security in Pond Inlet, there was no mention of difficulty obtaining food in Pangnirtung. Alcohol abuse was described as a safety issue for a child with a disability in one family. One fifty-one year old wife of a disabled gentleman stated casually that her entire family lived together in the house but did not describe this as a barrier.

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[16] Pseudonyms used here.

Pond Inlet

The regional nutritionist described food security as an essential component of participation for Baffin residents. Evidently this was a consideration for people with disabilities in Pond Inlet as food security was the first thing described as important in the focus group discussion.

> Food. A lot. We used to hunt and seal because we were in a camp. Now it seems the hard part is trying to eat. Feed our children because they don't eat traditional food like they used to.
>
> (56 year old Inuk woman with disability)

The cost of food is a contributing factor. One gallon of milk costs eighteen dollars. A small bag of groceries with spaghetti sauce, bottled water, and pop comes to seventeen dollars. Consequently, elders living on a fixed income have difficulty feeding adult children and grandchildren and will often go without food themselves. A twenty-eight year old woman with a disability described experiencing lack of food to eat because the funding had fallen through for her job. This is her story prior to the loss of her job and a subsequent impression of the result of combined social factors.

> I was drinking and dope, smoking dope a lot. Even now, trying to keep myself calm. I was tired. I didn't know who to talk to. I just kept things to myself. I tried to commit suicide a couple of times when we first came here because I really had a hard time with my stepfather.
>
> (28 year old Inuk woman with a disability)

> Another traumatic incident occurred in 2000 June 17th was the death by suicide of her boyfriend. A smile disguised a lump in her throat and deep-rooted pain at the many losses she had experienced: her relationship with her mother, the suicide of her boyfriend and feelings of non-acceptance from her new community.
>
> (Interview fieldnotes, Feb. 5., 2003)

Two health professionals mentioned over-crowded housing as a factor that compounds disablement in Pond Inlet. They felt that three generations of families living in one home causes lack of privacy and irritability within the family unit. Similarly, health professionals describe many accounts of domestic abuse but first hand accounts from people with disabilities were absent.

Summary Social Vulnerabilities

Social vulnerabilities like food security, suicide, and inadequate housing are most visible in Pond Inlet but certainly present in Iqaluit. "Getting food" in Pond Inlet stands out as a significant social barrier that may prevent people with disabilities from obtaining a basic level of nutrition. It appears that the prevalence of social vulnerabilities is lower in Pangnirtung. However, the negative impact that suicide has on people with disabilities in all three communities is startling. The gravity of this issue is illustrated by three first hand accounts of suicidal ideation by women with disabilities: two in Iqaluit and one in Pond Inlet.

6.3 Physical Environment

6.3.1 Weather, Accessibility & Equipment

Iqaluit

Iqaluit participants spoke passionately about lack of accessibility to buildings, poor road conditions, and inadequate equipment. Ten statements were made about poor accessibility alone and seven people described the combined pitfalls of weather *and* accessibility.

The infrastructure in Iqaluit was a barrier to participation. Lack of paved roads, bumpy roads and absence of sidewalks were all described as barriers to "getting around". Three of five study participants with disabilities used wheelchairs for daily mobility. An excerpt from

a focus group discussion in which three women with disabilities discussed roads demonstrates this concern.

Rebecca: When you go on the road, on the side of the road. Ah there is always a problem for me also. I always have to go on the . . . I can't go on the road. I'm so afraid I might be...
(general sounds of agreement from all participants)
Interpreter: Because there is no sidewalk?
Rebecca: Right, no sidewalk. The sidewalk is all sand.
Patricia: It's always slippery when you're walking.
Participants: Yeah, (general agreement)
Pitseola: I 'm always walking on the side but I go on the road so I can walk and people complain you might get hit so go on the side . . .. So I just, I just walk right through the road that's the only way.
Rebecca: I'm going to do that.
Pitseola: They can get the point when I'm doing this. I have no choice.

Iqaluit Focus Group II [17]

Accessibility to buildings was also described as a barrier. The absence of a wheelchair ramp at the Anglican Church and an elevator in Arctic Ventures (multilevel department store) were of particular note to participants. The non-Inuit participant brought up lack of accessible seating in the theatre, schools and arena. Furthermore, participants stated that un-shovelled ramps present an equally challenging obstacle.

Snow impedes peoples' ability to get around in Iqaluit. A fifty-nine year old wheelchair user described two instances when she got stuck in the snow. Her wheelchair is very old and the tires become covered in ice and snow very easily. One other participant also described the need for repairs on her wheelchair. Another twenty-year old female participant who uses forearm crutches for outdoor mobility gave an exasperated description of constantly falling on her back. The combination of snow and poor accessibility create a significant barrier to community participation in Iqaluit.

[17] Pseudonyms used for excerpt.

Pangnirtung

Similarly, but to a lesser extent in Pangnirtung, weather and accessibility have an adverse effect on people's ability to get around. Despite the work that has been done to promote accessibility in Pangnirtung, an analysis of the data gives the impression of mediocrity. Six statements were given that described poor accessibility outside and inside buildings, at the airport, and in homes. The following focus group excerpt reflects these sentiments.

> Well not all public buildings have wheelchair access yet. That should be made into some kind of law, public buildings have to have wheelchair access. Stores and stuff, are they considered public buildings? Not all the stores have wheelchair access. (general sounds of agreement) High arctic and where I work doesn't have wheelchair access. And at the convenience store up there. Pang video is though. It's got that long ramp you can go in.

Four statements depicted an optimistic view of accessibility in which examples were given of buildings that *were* accessible.

> And also I'm proud of the hamlet council. Like local businesses and the post office have wheelchair ramps. Public places they're doing something about the entrances. I'm proud of the hamlet council for doing that.

Accessibility responses from the housing department were described as superior to other communities.

> And now we are under the housing corporation. Everybody lives under the housing corporation. In Kinggait (Cape Dorset) their houses can't even be adapted to handicapped people but here we can. So that's a good example of Pang people more caring for disabled people than other communities.

More than accessibility itself, people described lack of equipment as hindering participation. Five individuals who used wheelchairs for daily mobility were mentioned in focus group and interview discussions. Two study participants used wheelchairs. One gentleman who used an electric wheelchair for mobility described this device as imperative for his mobility. He uses this chair outdoors and, to date, had not become stuck in the snow. On the other hand, obtaining proper wheelchairs that are appropriate for the weather and

terrain was a challenge for another gentleman. He paid for a chair himself with fundraising assistance from the community. Similarly, an elder who used a walker for mobility said that her wheels were inadequate for deep snow, a fact that has caused her to come very close to falling on several occasions. She does not have this problem in the summer.

Scooters were suggested for usage at the airport to transport people to and from the plane. Assistance with wheelchair assembly/disassembly at the airport would also assist with participation. Difficulty obtaining appropriate equipment, combined with deep snow and some inaccessible buildings present barriers to community participation in Pangnirtung.

Pond Inlet

Cold weather and the effect it has on outdoor mobility, safety and equipment was described as a barrier to getting around in Pond Inlet. Only one individual in Pond Inlet used a wheelchair for daily mobility. None of the study participants used wheelchairs for daily mobility. There was less emphasis here on accessibility. Six examples were given that describe the negative impact of cold, and/or equipment on participation.

Blizzard conditions and extreme cold restrict participation for individuals with disabilities in Pond Inlet. One gentleman with a disability described being trapped in his vehicle during a blizzard while his legs became progressively numb and his fear of freezing to death became a real possibility. Similarly, one mother of a child with a disability limits outdoor excursions with her daughter due to the cold. Walking conditions for individuals with a mobility limitation are made impossible during blizzard conditions.

> I find getting around really cold and tiring. It takes me fifteen to twenty minutes to walk to my work and get back home. When it's really cold, I slow down more. Is seems like I get weaker, especially during blizzards. I can hardly walk alone. I have to have someone holding me. (29 year old Inuk woman with a disability)

Icy roads and snowy conditions also make outdoor mobility dangerous:

> My walker, I have less trouble with it in the South cause there are sidewalks down there. But here there is snow and gravel and it's harder for the walker.
>
> (66 year old Inuk man with a disability)

The effect that icy roads and extreme cold have on equipment was also well articulated. One non-Inuit gentleman is unable to use his scooter in the winter due to icy road conditions. In the same way, another woman struggles to keep her plastic leg braces warm in the winter so they won't break.

The housing department was described here as being helpful. Lack of knowledge, however has resulted in "so-called" accessible houses for people with disabilities being built on stilts with several flights of stairs to enter. This was the only example given of inaccessibility. Absence of portable oxygen tanks for individuals with respiratory problems severely limited their ability to get out on the land. Exercise equipment to walk on and keep muscles strong was also described as something that would facilitate ambulation in Pond Inlet.

Summary: Accessibility, Equipment and Weather

Cold weather in North Baffin and heavy snowfall in Central and South Baffin create barriers to community participation for individuals with disabilities. Snow combined with poor accessibility in Iqaluit makes outdoor mobility particularly treacherous. Structural deficits like lack of sidewalks and poor road conditions combined with heavy traffic create additional barriers. In Pangnirtung and Pond Inlet weather combined with equipment needs present significant barriers. In the smaller communities accessibility seemed to occur when individuals with disabilities start to use mobility equipment. The process for equipment purchase and repair is unclear.

6.3.2 Transportation

Iqaluit

Transportation is a monumental obstacle for people with disabilities living in Iqaluit. A wheelchair accessible vehicle is accessed through Health and Social Services for use by residents at the Elders' Centre and by Iqaluit Homecare clients. However, it is used primarily for medical appointments and is not available to members of the public. Public transit was put in service in 2003 but is not accessible for wheelchair users. Round trip taxi fare is $10.00, a cost that is too much for residents on fixed incomes to pay. In fact, a young woman from Pond Inlet emphasizes that lack of "money in [their] pockets" makes it hard for people with disabilities from outlying communities to get around when coming to Iqaluit. The Iqaluit Homecare Co-ordinator also commented on this phenomenon.

> I think their ability to participate would improve if they could just get back and forth to things. It's really difficult and it's very costly to take taxis to things. Anybody who's in a wheelchair in the wintertime, it's almost impossible unless you are using the handivan to go anywhere. We had COPD client who didn't have a great deal of money and wanted to be able to use the handivan to go to church and it wasn't available.

This lack of available transportation for people with disabilities in Iqaluit has devastating consequences. A young woman with cerebral palsy who struggles to ambulate around Iqaluit comments on how lack of transportation affects her daily life.

> I have one big problem. I go to the hospital three times a week. I have no transportation. There's completely nothing for disabled people to go to a hospital or where you need to go. (exasperated and very emotional) There's no transportation and there is nobody to depend on. But the main thing that's a problem for disabled is if you need to go somewhere important or if you want to go see a family member. There is nothing ready to do that.

Pangnirtung

In Pangnirtung the "Bylaw Truck" was the primary means of transportation for individuals with disabilities. This is a large sport utility vehicle owned and operated by the town council that is used for various community functions. However, it is strenuous for people with disabilities to get into low vehicles like this and difficult for caregivers to assist.

One forty-two year old male community member expressed concern over the fact that the homecare vehicle was not being used for its intended purpose: "The nurses' vehicle was supposed to be used for handicapped people exclusively and I've never seen it used. It was supposed to be the number one reason for its use". Further discussion centred on the need for acquisition of a wheelchair accessible vehicle for use in the community. Five different participants reiterated this concern.

> Older people who go to Iqaluit in wheelchair have a very convenient thing. They have vehicles that take the whole wheelchair without sliding over. You can just drive onto the ramp and then it puts you in the car. There was money available to buy something like that at one point but we never jumped at the chance.
>
> (62 year old Inuk man with a disability)

Women emphatically and humorously said "humans are heavy". They felt that lifting someone in and out of a low vehicle was extremely difficult so a van would help immensely. Despite the fact that a bylaw officer is always available, participants felt that the growth of the community warranted a more accessible approach to transportation.

Pond Inlet

Concerns also emerged about transportation in Pond Inlet. Financial limitations and inefficient use of the homecare vehicle were cited as the most pressing issues. A homecare vehicle was recently purchased for transporting elders and people with disabilities to church,

shops and to the airport. However, blurred lines of authority combined with the absence of an available driver are barriers to the operation of this vehicle for its intended purpose. It *is* used for some elders' functions but cannot be accessed publicly. Furthermore, participants gave frequent accounts of lack of transportation inhibiting their ability to get out. A sixty-two year old gentleman with a disability stated simply, "... and also transportation, going somewhere, we don't have that".

Physical ability may limit one's ability to start a snowmobile but people with physical disabilities are successful in modifying equipment to suit their needs. In fact, purchasing and maintaining a snowmobile is a greater obstacle than ability. One young woman was saving money for a skidoo as she felt this would greatly assist in her daily outdoor struggle. Transportation is a significant barrier to participation in Pond Inlet. The inefficient use of the homecare vehicle combined with inability to finance taxis and skidoos were the most noted barriers.

Summary Transportation

Lack of adequate transportation is a substantial barrier to participation in this region. It is most evident in Iqaluit and Pond Inlet where formal and informal means of obtaining transportation are not working effectively.

In Pangnirtung, however, people do emphasize that they can always get a ride somewhere. Family and the Bylaw Officer provide transportation for people with physical disabilities. Pangnirtung residents would still like to take accessibility a step further and work on obtaining a wheelchair accessible vehicle for their community.

In Pond Inlet transportation is the primary barrier to participation for people with disabilities. Health and Social Services acts like the gatekeeper of the homecare vehicle, preventing it from being used for its intended purpose: a method or transportation for elders and people with disabilities. Another significant barrier is lack of financial ability to own and maintain skidoos. Decreasing family support in provision of transportation was also indicated.

6.4 Chapter Six Summary: Facilitators and Barriers to Community Participation

6.4.1 Iqaluit

The degree of informal support was low in Iqaluit and can be viewed as a barrier to community participation for people with disabilities. Although family was described as being important generally, specific examples of where and when this support occurred were absent. It is possible that family assistance is under-reported because this is an assumed, intrinsic part of Inuit life. In other words, the cultural expression of family support may differ from Euro-Canadian expression.

Participants felt that community attitudes were generally negative toward people with disabilities. This is a barrier to community participation and can be linked with the great sense of isolation and loneliness that women with disabilities in Iqaluit felt. Homecare was seen as a support for people with disabilities and facilitator to community participation. Value was placed on the importance of physicians and health workers, mostly in the context of medication prescriptions. One participant felt strongly that Healthcare through the Government of Nunavut was lacking and noted a low level of available counselling services.

A large number of barriers also exist in the physical environment. Most notable is the combination of heavy snowfall with inaccessible road and building conditions. Outdoor

mobility is treacherous and frequently impossible under these conditions. The lack of accessible public transportation for the capital city is a political barrier. A bus system has been put in place but is inaccessible for wheelchair users. One accessible van is present in Iqaluit but is used only by direction from Health and Social Services for medical appointments.

6.4.2 Pangnirtung

Pangnirtung stands out as a community that has many facilitators for people with disabilities across both the social and physical environment. The Inuit cultural value placed on sharing and reciprocity appears to facilitate the inclusion of people with disabilities. As a result, informal family support and community support for daily living and for traditional activities is abundant. Integration is seen in attitudes and knowledge as people with disabilities are viewed as being just like everyone else. Knowledge of southern systems and views on disablement also seem to facilitate participation. Contextual descriptions of accessibility and healthcare ideas also appear to have facilitated disability advocacy within the community.

Formal support is present through homecare and through health and social services. Participants feel that the level of rehabilitation service provision is inadequate but largely view homecare as a facilitator to participation. The physical environment is better here than the other two communities but participants emphasized that improvements can be made. Lack of a wheelchair accessible vehicle was deemed by the community to be the largest physical barrier to participation.

6.4.3 Pond Inlet

Physical disability is particularly difficult for residents living here. Most participants emphatically describe just wanting to get out in the community and on the land. The level of informal support here for people with disabilities is low. Family *are* an important source of support but help less frequently than in years gone by. Simultaneously, homecare is playing a larger role in assisting people with disabilities. Informal support from community members is also sporadic and inconsistent. An overwhelming sense of isolation with no one to talk to is, in part, the result of these deficient sources of support.

The physical environment in Pond Inlet is the harshest of all three communities. Extreme cold wreaks havoc on one's ability to get outdoors. Icy, steep roads within the community are impossible to negotiate. Obtaining transportation is difficult. The homecare vehicle is not being used publicly, taxi fare is expensive, and snowmobile purchase and maintenance is unaffordable. Social vulnerabilities like food security, suicide and family violence compound the present barriers for people with disabilities in Pond Inlet. Table 8 summarizes facilitators and barriers to community participation in Iqaluit, Pangnitung and Pond Inlet in the Social and Physical Environments.

Table 8: Facilitators and Barriers to Participation by Community

	Barriers	Facilitators
Iqaluit		
Social		
Informal	Negative Attitudes Decreased Informal Support Diminishing Family Support	
Formal	Long Distance for Medical Travel Lack of Available Counselling Emphasis on Acute Care	Medications from Physicians Presence of Knowledge - South Support for Daily Living: Homecare
Physical	Snow Depth Unpaved Roads Absence of Sidewalks Inaccessible Buildings & Housing Absence of Accessible Transportation	
Pangnirtung		
Social		
Informal		Emphasis on Community Sharing Integrative Attitude High Level of Informal Support: family and community
Formal	Absence of Physiotherapist Lack of Trained Homecare Workers Low level of Rehabilitation Resources	Presence of Knowledge – Disability Support for Daily Living: Homecare
Physical	Securing Equipment Some Inaccessible Stores Absence of Accessible Transportation	Bylaw Officer: Transportation
Pond Inlet		
Social	Low level of informal support: family and community Absence of Knowledge – Disability	Support for Daily living from Homecare
Physical	Extreme Cold Hilly Terrain Absence of Transportation Limited use of Homecare Vehicle Decreased Financial Capacity: taxis, snowmobiles.	

Chapter 7

Results:
Participant Suggestions for Future Action

This chapter summarizes suggestions made by participants in focus groups and individual interviews to enhance participation for individuals' with disabilities. It is divided into three sections, one on each community: Iqaluit, Pangnirtung and Pond Inlet. A table summarizing participant suggestions (Table 9) and descriptive summary is located at the *end* of the chapter. Analysis of focus group and interview transcripts was performed to create this chapter.

7.1 – Iqaluit: Gearing for Action

When Iqaluit participants were asked about recommendations for the future, discussion focused on facilitators and barriers regarding accessibility, housing and transportation. However, concrete examples of solutions were absent from the discussion. All participants did agree that greater public awareness and advocacy about disability was needed. Anita[18], a passionate and intelligent Inuk woman with a disability, took it upon herself to incorporate focus group concerns into a document outlining rationale and logistics for the creation of a disability board. This document represents Anita's own experiences but also reflects concerns brought up by focus group peers in this research. The emphasis on counselling reflects loneliness depicted by participants. The push for advocacy is addressed through home visits to enhance representation of peoples' needs. Training and education is represented in the need for public awareness. This is the researcher's initial impression of this gesture:

[18] Pseudonym used here.

> It was sketchily hand printed in black ink. This document must have taken her days to do with her badly deteriorated, and weak hands. A lot of time and effort must have gone into this hand written paper (20 pages). She said that she wanted to contribute something to help move this disability project forward and would like me to have this for future ideas about a disability and/or proposal with the government.
>
> (Researcher's Fieldnotes, Jan.30, 2003).

The following is a summary and analysis of this document.

7.1.1 Analysis of Advocacy Document

This document was created in order to have a proposal outline for federal government funding for a disability board. The yearly operational monetary estimate for this organization was $60 000. Ideally, a board of five to nine people would be chosen from the community by advertising positions publicly. Appendix F contains a summary of board member positions and responsibilities. There is an emphasis throughout the document on fiscal responsibility. The annual budget was broken down into administrative needs, and capital expenses that totalled $25 000 dollars. One recommended use of capital funds was the purchase of an accessible vehicle for Iqaluit the second was for travel and accommodation for conferences.

Three major program areas were described in the document: education and training, assessing needs, and counselling. Many of these program areas reflected community needs of focus group participants. In fact, under a section headeing, "Community Needs", Anita summarized comments expressed in the focus group by women with disabilities.

> For a long time now, Inuk disabled peoples have been neglected in access to wheelchairs. There is no sidewalk for wheelchairs or houses for them. There is not enough concern about material needs that are made for disabled peoples. They need support to work together to come up with money for beds and houses made for individuals with disabilities. Education to the public using our own ideas on news from Disabled Peoples!
>
> (50 year old Inuk woman with a disability)

Education about health issues and community concerns would be taught by a rehabilitation professional. A counsellor and board member would make home visits twice

per month. This would provide an opportunity to discuss, from the perspective of disabled people, ongoing needs and concerns. These concerns would be brought back to the board to ensure general representation of all people with disabilities in the community. The goal would be for people with disabilities to feel like part of the community. Group and individual counselling sessions would also be provided through the disability board. It was recommended that elderly Inuit also provide cultural counselling and give education on Inuit ways. Appendix G contains an original excerpt from this document that demonstrates a culturally appropriate counselling strategy.

Diversity in board selection was emphasized. An Inuit board of equal gender, mixed with some non-Inuit, was suggested. Hypothetical profiles of five Inuk board members of various ages and gender with complimentary life experiences were given. One example depicted Ollollo, a unilingual elder with vivid experiences of shamanism, strong beliefs in land and animal medicines, and experience in counselling the sick. Conversely, another young Inuk woman was described who was curious about health and sickness and very outgoing. She could read well but does not understand new English words.

7.2 Pangnirtung – Building on Strengths

Future recommendations in Pangnirtung were abundant and several strengths exist in this community that can be built upon. Various ideas for training and education, services, and advocacy were relayed from community members, people with disabilities, and caregivers. Many of these recommendations could fit into or be built around existing successful programs. A forward-looking approach to assessing need included discussion about an elders' facility and affirmed that a wheelchair accessible vehicle was essential.

7.2.1 Training and Education

Participants feel that a greater amount of training must be done for family members, homecare workers, and health professionals.

> The workers who get paid for helping elders and handicapped they do a great job. They do a great job in keeping the patients safe but they need more training.
>
> (62 year old Inuk man with a disability)

> I feel that people with disabilities should all have workers or somebody looking after them. Even if they have family members that are helping out then they, she feels that there should be at least somebody there working with them.
>
> (51 year old Inuk caregiver)

One non-Inuit health professional made a general statement about the need to train more people to deal with disabilities in the future. He noted that now people just "kick in" because unpaid caregiving has always been an integral part of the Inuit way but this may not be the case in the future. More specifically, another non-Inuit health professional says that education and training for people who are family members or care givers is important. He comments on the impact training might have:

> Because when people have such additional knowledge and skills they can basically do much more. They can actually compensate considerably for the lack of professional services that will always be here in the North.

Furthermore, he feels that nurses who may have no professional background in disability and rehabilitation need detailed, regionally appropriate resource materials and training. One example was an Internet resource guide for disablement in this region.

One community member and one individual with a disability, in two separate focus groups, brought up the absence of a physiotherapist. The following is a response to this concern from a sixty-two year old gentleman with post-polio syndrome in the second focus group.

> It shouldn't take a whole lot of training to do physiotherapy. Jeannie helps me with that. She was shown by the doctor how to help someone with my joints and the stuff I can't move. It shouldn't take a whole lot of training. They should be able to learn it.[19]

Following this statement, the researcher inquired about the concept of people being trained in physiotherapy skills locally. The response to this was overwhelmingly positive. Training to ease the burden of caregivers was also brought up. The wife of a gentleman with a disability felt that people with a family-member as caregiver should also have the assistance of a trained homecare worker. In Ottawa, she had seen another woman receiving instruction from a therapist alongside a homecare worker. Members in the first focus group felt that homecare workers should be employed for a greater number of hours.

7.2.2 Advocacy

The second focus group unanimously agreed that setting up a committee in Pangnirtung would be a good idea for the future. The term "caregivers group" was used to describe the make-up of a group. A brief discussion about the potential benefits of a committee ensued:

> I think it's a good idea to set up a committee because things that are planned can be carried out better with a committee overseeing them. Trying to do it as an individual can get very difficult. It's better to have a group behind you.
>
> (52 year old female Inuk community member)

> They could bring out more programs. Talk about the programs that are available for handicapped people. They could also have focus group discussions on a specific topic, better ideas, more diverse ideas.
>
> (42 year old female Inuk community member)

Similarly, the idea of a town co-ordinator emerged from community members in the first focus group. One forty-two year old community member was distressed that a Hamlet Co-ordinator was present for many issues but a "handicap people's co-ordinator" was not in existence. He also felt strongly that education should be directed toward school-aged children

[19] Pseudonym used here.

in order to create awareness. Furthermore he emphasized that mental health should be a primary focus. Connecting with others in neighbouring communities who have a similar disability was suggested as a strategy for maintaining mental wellness.

7.2.3 Model for Greater Integration

In an in-depth interview, one health professional stated that it is presently the department of health that is ultimately responsible for meeting the special needs of individuals with disabilities. He went on to describe what he perceived to be a more holistic approach and stated that an advisory board was needed to oversee a co-ordinated system of resources across many sectors. A more integrative approach for improving participation for Pangnirtung residents with disabilities in the future was outlined.

> Any form of rehabilitation service that is being developed in our communities, needs be built on a different philosophy. It needs to be built first of all on the strengths then you will really be able to ... provide support. Not just support, but also integrate people, who have special needs so fully into the society and into the community that their physical disabilities will become really, not a big thing. (50 year old male non-Inuit healthcare provider)

The model that he envisions (Figure 6) sees an intake co-ordinator executing a comprehensive needs assessment for an individual who may have a physical disability. A co-ordinated effort between a core of health professionals and among virtually all economic and social sectors would allow the needs of the individual, family and community to be met.

Dietetics, recreation, occupation therapy, physiotherapy, mental health services, education and professional development were professional areas that would have a key consultative role in the needs assessment. Education by these professionals would be directed to other sectors like the Hunters and Trappers Association, The Arctic College, and to retail outlets in Pangnirtung. Notably, mental health was emphasized here as a key component of any

successful rehabilitation program. The Pangnirtung Homecare Program would be intimately involved and would receive training in more medical aspects of client wellness. Homecare workers would address physiotherapy, nutrition and nursing needs. In essence, there would be a community agency or intermediary providing education to the family and to the person with a disability.

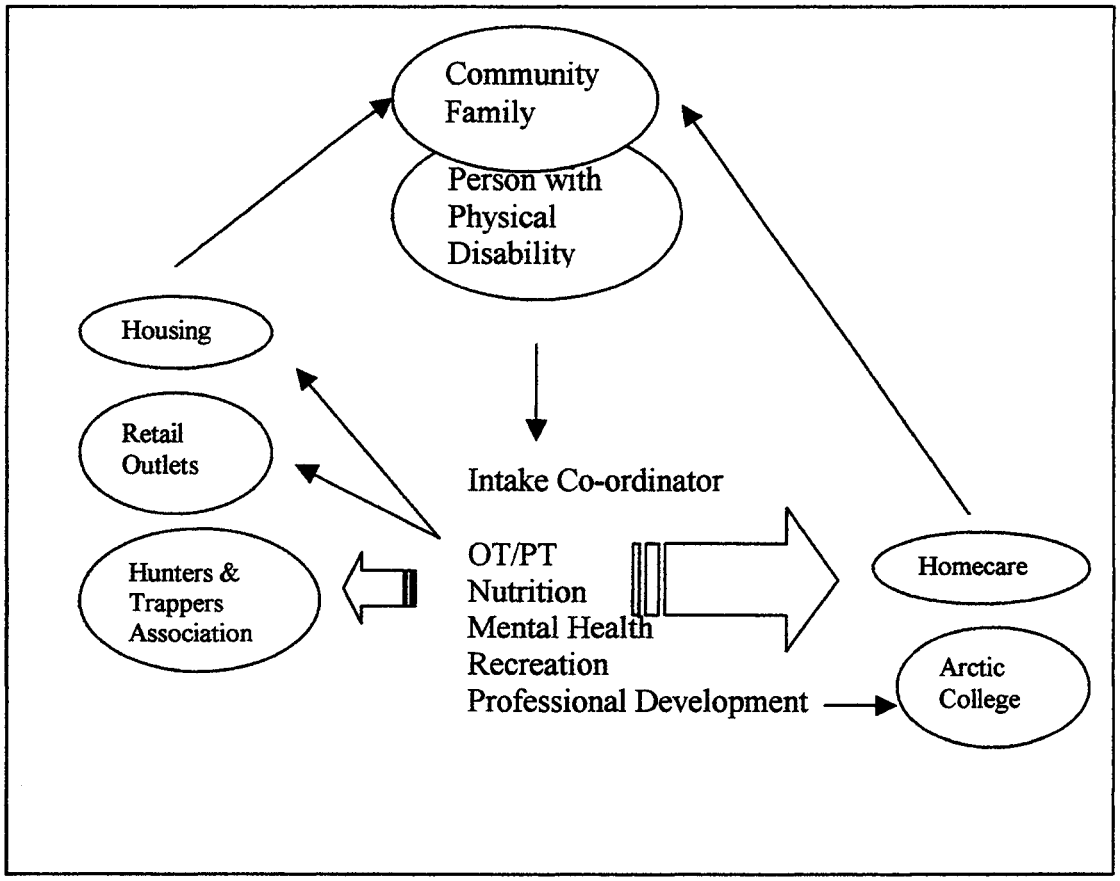

Figure 6: Model of Program Delivery for People with Disabilities. (Adapted from Pangnirtung Interview: 49 year old Health Provider).

Participants also felt that a facility was needed for people who required twenty-four hour care. Inquiries were made about the facility in Iqaluit. Participants in the second focus group felt that the development of this concept in Pangnirtung warranted considerable thought. There was a great concern over the absence of a wheelchair accessible vehicle. Although the need was expressed, a clear direction for obtaining this in the future was not addressed.

7.3 Pond Inlet: Simmering Awareness

Suggestions for future improvements were sparse in Pond Inlet. Recommendations were made by health professionals to improve transportation, and provide portable oxygen for homecare clients. Focus group participants and one interviewee described getting together for regular meetings in the future as something that would help.

One health professional suggested providing taxi vouchers to people who are unable to get around. He remarked that it would be more cost-efficient to spend one hundred thousand dollars on taxi passes than to pay for getting an appropriate vehicle and driver to Pond Inlet. He also thought that improvement in lines of communication between health professionals would allow a common directive to be achieved with regard to the homecare vehicle. Another health professional suggested that a driver for the homecare vehicle would improve participation for individuals in the future.

When focus group participants were asked . . . "Where should we go from here?",

the response from participants was . . . "It's hard" and then a long silence followed. A few suggestions were then made. One came from a woman with a disability. "Just like what's been done. Like we went home and then someone came to pick us up now they're here. If someone could do that." She went on to say that having a visitor to their house would be helpful. Three focus group participants suggested an elder's centre. They felt that this centre would help with transportation because they are in need of transportation.

One thirty-year old caregiver suggested that teaching and training about disability was needed in the schools to facilitate greater integration of children with disabilities. She was exhausted and felt that offering respite for children with disabilities might also give

caregivers an opportunity to rest. But most importantly she described unity as essential. "Getting together is the basic part. Get together. Even for parents it's very hard." The three main recommendations from Pond Inlet when asked about the future were; increasing unity of people with disabilities and caregivers, improving transportation through taxi vouchers or a driver for the homecare vehicle, and providing education and training about disability in the schools.

7.4 Chapter Seven Summary

Iqaluit participants provided future direction by stating the need for better transportation, and greater representation for people with disabilities. The document created by one of these focus group participants is invaluable for its content as it accurately depicts solutions to the expressed needs of participants with disabilities. As a community, Pangnirtung presented the largest number of suggestions for future action. The majority of suggestions centred on training, advocacy, and a new model for service delivery. A wheelchair accessible vehicle for transportation also topped the list of priorities. Pond Inlet had few suggestions for future action. Most suggestions came from non-Inuit health professionals who placed an emphasis on transportation and provision of portable oxygen therapy. There may be a cultural explanation for variations in expressing need between the communities. Table 9 lists and describes suggestions from participants in all three communities.

Table 9: Summary of Suggestions from Participants

	Suggestion	Description
Iqaluit	**Creation of Disability Board**	**Advocacy and ongoing community feedback.** **Accessibility** **Transportation** **Education and training to community, PWD and family members.** **Attitudes** **Counselling:** **Elders Wisdom, and Inuit ways.** **Mental well-being**
Pangnirtung	**Creation of Caregivers Group**	**Forum for addressing disability issues** **Care giving, accessibility to buildings and accessible vehicle.**
	Training and Education	**Physiotherapy & other skills to family members and homecare workers caring for PWD.** **Physiotherapy skills taught to homecare workers:** **Knowledge** **Caregiving** **Access to Equipment**
	Resources for Health Centre staff.	**Comprehensive, Region Specific Internet resources for PWD.** **Continuing education for nurses on rehabilitation specific skills.**
	CBR Model of Service Delivery	**Regional Inuit Disability Committee as advisory to Health and Social Services.** **Region specific intake co-ordinator develops personalized needs assessment for PWD. Health professionals direct education to sectors in community like housing, homecare, hunters and trappers association, arctic college and retail.**
Pond Inlet	**Improved Transportation**	**Driver for Homecare Vehicle** **Taxi Vouchers/Discounts** **Portable Oxygen to PWD**

Chapter 8

Discussion

8.1 Introduction

This chapter contains a reflective analysis of the study results. With the original research questions as a point of reference (Table 10), it highlights revealing and perplexing discoveries while demonstrating how these findings tie in with existing literature. For example, why are facilitators and barriers to participation in the communities "the same ... but different" for people with disabilities in these three Arctic Canadian Communities?

The first section will be entitled, "Iqaluit, Pangnirtung, & Pond Inlet: Different Portraits of Disability". Links will be drawn between environmental factors in the community profiles, degree of participation, and existing barriers and facilitators in each community (chapters four, five, and six) to summarize the study results. The discussion will then focus on how acculturation to Euro-Canadian values and systems, gender, heterogeneity of the community, and socio-economic status may cause the significant variations in participation between communities.

Geographical features of rugged terrain, and relentless Arctic climate also provide a backdrop to discuss the presence of physical barriers across the North. The universal existence of these barriers and policies in place to address them will be discussed in the second section on "Transportation and Accessibility: Universal Barrier".

In the final section, the researcher will integrate the existing body of literature with analysis of facilitators and barriers and participant suggestions in order to look to the future and provide recommendations for action. A conceptual model of CBR in Northern Canadian Regions is presented based on results and suggestions from participants. Furthermore, an

exploration of the gap in existing literature on this subject will demonstrate the importance of a social, insider perspective when attempting to provide a foundation for CBR programs. These areas of reflection address the main purpose of the study and are discussed under the section "Contexual Disability Study and Community Development in the North".

Table 10 Study Purpose and Research Objectives

Study Purpose
To understand, from the perspective of Inuit and non-Inuit living in three diverse Baffin Island communities, how community participation could be enhanced for people with disabilities.
Research Objectives
1. To establish a descriptive community profile of Iqaluit, Pangnirtung, and Pond Inlet that will distinguish and describe their environments.
2. To compare and contrast facilitators and barriers to community participation for individuals with disabilities living in these communities.
3. To describe solutions for change from community members that they feel will improve participation for Inuit with disabilities in the future.

8.2 Iqaluit, Pangnirtung, &Pond Inlet: Different portraits of disability.

8.2.1 Summary of Results

Inuit living in the Baffin Region have undergone enormous transition within their communities over the past century. As the inhabitants of an extremely remote part of Eastern Arctic Canada, Inuit people have had sparse, intermittent contact with the western world until the 1950's. First whalers, then fur traders, missionaries and eventually the Canadian Federal Government have imparted their values, traditions and systems on the Inuit thereby influencing Inuit life. As the same time, a momentous transition for Inuit from living on the land to living in communities has offered people with disabilities a certain degree of rescue from ostracism or even death. Now Inuit people with disabilities struggle to find a new role

within the modern Inuit community. This role varies between communities based on the degree of exposure to Canada's mainstream influence.

Pangnirtung has a supportive, inclusive environment for people with disabilities. Individuals with disabilities participate in advocacy, land activities, community politics, shopping, elders' teas, and bingo. This supportive environment is less evident in Pond Inlet. Here, people with disabilities go out on the land less frequently, report not having people to talk to, feel a sense of isolation, are afraid of falling and freezing outdoors, and report not visiting each other as often. The reality of this situation is made worse for individuals in Pond Inlet who revere land activities and value independence and fortitude. The most notable discrepancy in the social environment is the low level of informal support reported to exist in Pond Inlet opposed to the high level of informal support reported to exist in Pangnirtung.

In Iqaluit, there are numerous barriers in the social and physical environments that lead to a sense of isolation. Individuals with disabilities here experienced low levels of paid employment, loneliness, decreased participation in land activities, frequent falls, inability to attend church and shop, and difficulty attending appointments. Inuit people with disabilities have become marginalized amongst an influx of non-Inuit people, a building boom and the most rapid shift from subsistence to wage-based economy of all Baffin Island communities. All participants except one were women, a fact that reveals an interesting gender perspective on disability in Iqaluit.

8.2.2 Acculturation in Arctic Communities

In Pond Inlet, conflict between young and old people and between males and females regarding their roles is evident. The existence of this type of conflict in Inuit families adjusting to cultural change has also been documented in the literature (Borre, 1991; Briggs,

1995; Stairs, 2001; Bjerregaard, 2001; Bjerregaard, 2002). Bjerregaard describes this type of stress in remote Inuit communities of Greenland as "acculturation stress", a phenomenon that arises when a community undergoes transitions from a traditional society to a modern industrialized society (Bjerregaard, 2002). The transition from subsistence to wage based economy, increased contact with mainstream Euro-Canadian values and an influx of non-Inuit into communities are described as contributing factors to acculturation stress. Other studies also attribute high rates of suicide, social problems, and obesity in Inuit communities to acculturation stress (Bjerregaard, 2002; Hodgins, 1997; Rode and Shephard, 1995; Rode & Shephard, 1993).

The community profiles (Chapter 4) demonstrate that Pond Inlet is traditional, isolated and in the midst of a significant transition to wage economy. These environmental observations are significantly different from those in Pangnirtung. Pangnirtung has had greater interaction with Euro-Canadian culture, has been less isolated and has had a longer and more consistent exposure to wage based economic opportunities. As a result, it is reasonable to assume that Pond Inlet may be facing a greater degree of "acculturation stress" than Pangnirtung. This stress significantly influences the extent to which Inuit with disabilities participate in their communities.

8.2.3 Acculturation: Attitudes

The maintenance of traditional values in the face of enormous social transition in Pond Inlet may affect how elders with disabilities perceive physical disability. Few elders in Pond Inlet with disabilities describe activities that could be deemed productive. Productivity is closely identified with meeting the basic survival needs of humans. In the recent past, North Baffin communities worked together in the natural environment to obtain food, shelter and

clothing. This type of productivity has changed rapidly in the face of a transition from subsistence to wage based economy. In the absence of participation in land-based activities, elders with disabilities in Pond Inlet may feel deficient in their sense of contribution. Disability in this context may have a greater impact on emotional well-being than in other communities.

Animal/human relations and social relations are at the heart of Inuit well-being (Borre, 1991; Shea, 1991; Stairs, 1992; Pauktitut, 1998) The process of hunting animals, specifically seals, and communally eating them is believed to give life to the body and the soul of humans. When deprived of seal blood, for example, it is believed that physical and mental illness will follow (Borre, 1991). In the absence of country food for prolonged periods, many Inuit believe that they will die. Consequently, Inuit with disabilities living in a more traditional community like Pond Inlet may be more affected by their inability to hunt, prepare, and eat country food than those dealing with a similar impairment in another community more exposed to Euro-Canadian values.

Individuals in Pangnirtung have had more exposure to the concept of physical barriers inhibiting participation and to Euro-Canadian ways of ameliorating disability through improved accessibility and advocacy. This may be why they possess greater sensitivity and more inclusive attitudes toward people with disabilities. A greater number of individuals in Pangnirtung used wheelchairs and walkers for mobility and an advocacy movement was already in place. Conversely, in Pond Inlet there were no adults in the community who used wheelchairs and few who used mobility aids. It is known that an individual's exposure to disability is linked with more positive attitudes toward individuals with disabilities (Grayson & Marinin, 1996; Al-Abdulwahab & Al-Gain, 2003; Choi & Chow, 2001). Positive attitudes

at a community level may create an environment that is more inclusive for individuals with disabilities.

8.2.4 Acculturation: Gender Roles

In Pond Inlet, a transition from women performing in predominantly care-giving roles to greater participation in the paid work force may also be creating a gap in the number of people available to provide informal support to people with disabilities. In both communities, female children and sisters were often employed and therefore assisted less with care-giving roles. The difference is that people in Pangnirtung seemed more comfortable with the idea of homecare filling in this gap and less emphasis was placed on traditional gender roles. In Pond Inlet there seemed to be a reticence to accept formal support.

Blackmer and Marshall (1999) speak of service provider ignorance to intrinsic dependence on family and community members for assistance with activities of daily living and functional mobility tasks. This indicates that an intrinsic dependence on women fulfilling these roles exists in all Aboriginal communities and should be accommodated for by health professionals. It is evident from this study of Baffin communities, however, that the dependence on family and community members varies depending on many environmental factors. As noted above, women are now working and less available to carry out this typically gender assigned role.

The assumption that female family and community members provide a great deal of assistance to people with disabilities in Aboriginal communities is common in the academic world. In reality, it may be an unrealistic, out-dated, misconception. This issue has been expressed by "Pauktuutit Inuit Women's Association". In an annual meeting, the president expressed concern over the fact that Inuit women are held responsible for picking up

caregiving responsibilities within the communities (Inuit Tapirisat of Canada, 2000). It is evident that gender roles within the family are dramatically changing in Inuit communities. Now, formal support has an important role to play in easing the stress level of tired female caregivers and enhancing participation for individuals with disabilities.

8.2.5 Inuit women with disabilities: Gender Inequality

It has been well documented in the literature that women with disabilities are subject to greater exclusion and isolation than men with disabilities (Albrecht, 1997; Begum, 1992; Fairchild, 2002; Fawcett, 1996; Roeher Institute, 2001; Human Resources Development Canada, 2003). Coincidentally, all participants with disabilities in Iqaluit were women. These women felt immense barriers in their physical and social environments. Few had paid employment and many described moments of suicidal ideation and incidents where they had picked themselves up from an emotional sense of rock bottom. These findings are cohesive with literature documenting how the combination of disability, poverty and female gender within Aboriginal communities interact to prevent full community participation (Demas, 1993; Durst & Bluechardt, 2001; National Aboriginal Network on Disability, 1992; Ng, 1996).

Aboriginal women with disabilities expressed this perceived inequality in a document entitled Voices in the Wilderness (National Aboriginal Network on Disability, 1992). They claim that acculturation has enhanced their sense of marginalization from the community. Traditionally, women and men were seen as equal partners in the life process. Since contact with European societies, the role of Aboriginal women in Aboriginal society has diminished. One women stated, "In my community, men with disabilities are generally treated better than women with disabilities. People may feel sorry for them, but they are given respect"

(National Aboriginal Network on Disability, 1992, p. 2). Often, Aboriginal women with disabilities are expected to assume the role of unpaid baby sitter and homemaker to the rest of the family unit.

8.2.6 Heterogeneity of the Community

The heterogeneity and exposure of Iqaluit to Euro-Canadian culture may be one explanation for the marginalization of people with disabilities here. At a community level, Iqaluit is now a group of sub-cultures: various Inuit groups from the Baffin Region, Francophones, and Anglophones. Loveland (1998) states that, "people with disabilities who live in societies in which residential, educational and social segregation of subcultures exists may have little opportunity to interact with other people who have similar disabilities". The immense sense of isolation expressed by participants in this study within a melting pot of cultures in Iqaluit is consistent with this premise. The presence and influx of different families from across the high arctic in Pond Inlet compared to a few well-established families in Pangnirtung may also contribute to the sense of isolation experienced in Pond Inlet.

In the context of disability, marginalization is described as a situation in which disability-related needs are not identified and supported and the person is not involved in the community (Minnes et al, 2001). This appears to be the case in Iqaluit. Theories of assimilation provide additional insight into the perceived marginalization of participants in Iqaluit amongst a flurry of government and economic activity, abundance of Inuit organizations and high level of health services. Assimilation is described as the process through which people in subcultures adopt traits from the larger culture (Loveland, 1995; Dyck, 1998). This results in loss of cultural traits and replacement of new ones. This concept is evident in Iqaluit. The emphasis has changed from traditional Inuit values like co-operation

and collectiveness to adoption of typically Euro-Canadian values like individual work and achievement as a measure of accomplishment.

8.2.7 Social Vulnerabilities and Socio-economic Status

Family and informal support systems play a significant role in assisting people with disabilities in all cultures (Grady, 1995; Ravetz, 1998; Thorburn, 1999; Tryssenaar, & Tremblay, 2002). In a model that reflects one's personal community, Grady places family/friends and informal support in closest proximity to the person (Grady, 1995). Ravetz suggests that poverty may create conditions in which family act as a barrier to community participation rather than a facilitator (Ravetz, 1998). In situations of poverty in which the entire household is subject, people with disabilities will be particularly vulnerable (Whyte & Ingstad, 1998).

Poverty combined with visible social vulnerabilities like suicide, alcohol and drug abuse, and family violence are visible realities in Pond Inlet. These social vulnerabilities are consistent with those documented in the Circumpolar Inuit populations (MacMillan, 1996; Inuit Tapirisat of Canada, 2000; Kirmayer, Malus, Boothroyd, 1996). This may influence the amount of support that is available to be offered by family members in Pond Inlet. Furthermore, it is evident from statistical profiles of these communities (Table 11) that Pond Inlet has a low level of employment, the highest number of people per dwelling and a slightly lower level of high school graduates. The break-down of those unemployed was not available.

Table 11: Social and Economic Indicators for Iqaluit, Pangnirtung and Pond Inlet (Adapted from Statistics Canada, 2003).

	Employment	Unemployment	Highschool Diploma Aged 20-34	People/Dwelling
Iqaluit	74.5%	9 %.	31%	2.9
Pangnirtung	51%	25%	36%	3.6
Pond Inlet	43%	23%	27%	4.2
Nunavut	56%	17 %	27%	3.7
Canada	62%	8%	-	2.5

Socio-economic conditions have been alluded to as a contributing factor to disablement in Aboriginal populations (Canada, 1993; Demas, 1993; Durst & Bluechardt, 2001; Frankel, 1998; Robarts, 2002). Furthermore, when unemployment is a general problem in a community, disabled people are not likely to be employed (Whyte & Ingtad, 1998). "Double disadvantage" is a common term used to describe the presence of disability and of the existence of poverty in Aboriginal Canadians. The results of this study in the Baffin Region also suggest that socio-economic status and disability are intertwined in the fabric of the social environment.

8.3 Transportation and Accessibility: Universal Barriers

In Iqaluit, a community in flux between traditional ideals of inter-dependency and North American expectations of individuality, physical barriers in the environment exist in abundance. Pangnirtung and Pond Inlet also experience these barriers, perhaps to a lesser extent. Transportation was a significant barrier to participation in all three communities.

In Iqaluit, there was a lack of accessible buildings, housing, and public transportation. This was a greater barrier to participation than in the other two communities. In Pangnirtung, informal support facilitated transportation but community members still felt they needed an accessible van. In Pond Inlet, regulations dictated and limited the use of the homecare vehicle, preventing people with disabilities from having autonomous access to public transportation. High snow depth and extreme icy conditions compound the infrastructure problem of lack of side-walks and paved roads.

The role of the built environment in the oppression of disabled people in North America has been analysed (Dejong, 1981; Hahn, 1987; Marks, 1997, Marks, 1999; Crewe & Zola, 1984). This analysis has been based on ideals of wealthier countries in the world and accordingly has been built on values that emphasize independence not interdependence (Loveland, 1998). Nonetheless, the development of policies that address removal of barriers in the developed world has evolved from this type of analysis. Government policies in Canada are beginning to address barriers to access of buildings like these that make it difficult for individuals to live independently (Canadian Disability Rights Council, 1991; Canadian Mortgage and Housing Corporation, 1992; Ontario Human Rights Commission, 2003) The Human Rights Commission of Ontario (2003), for example, encourages barrier-free design in the construction and renovation of buildings.

The government of Nunavut, however has not come as far. There is an absence of a territory wide policy on barrier-free environments for people with disabilities in Nunavut. However, the human rights act of Nunavut states that Nunavut... "has a responsibility to guarantee that every individual is afforded an equal opportunity – failure to provide equality of opportunity threatens development and well-being of all persons in the community."

In his paper on government policy innovations, Dunn (1997) notes that people with disabilities living in rural areas of Canada experience grave difficulty obtaining accessible transportation. This reflects the frustrated sentiments expressed by participants in the Baffin Region. Dunn documents a growing trend toward accessible, government subsidized taxi programs over accessible vans and mini-buses in British Columbia, Alberta, New Brunswick and Ontario. In Vancouver and Prince George, "taxi saver" coupons are sold for 50% of their value to individuals with disabilities. A greater amount of dignity was associated with autonomous use of taxi. This was preferable to long waits and inconvenient schedules associated with "handicapped" buses.

The Standing Committee on Culture, Education and Health is a committee that serves the Legislative Assembly of Nunavut (Legislative Assembly of Nunavut, 2003). This committee may provide a political access point to address the unique combination of snow depth and extreme cold with physical inaccessibility as one of the barriers to equal opportunity for all people in Nunavut.

8.4 Contexual Disability Study and Community Development in the Arctic

8.4.1 Existing Body of Literature

A social perspective on disablement in Inuit communities is noticeably absent from the literature. Although general exposure to the issue of disability in aboriginal and Inuit populations has evolved over the past decade (Baffin Regional Health Board, 1994; Canada, 1993; Canada, 1994; Canada, 1996; Canada, 1998; Canada, 2002; Durst & Bluechardt, 2001; Frankel, 1998; Larson, 1986; Ng, 1996; Nuu-Chah-Nulch Health Board, 1989), a more holistic look at this phenomenon has not been described. This study offers a more holistic portrait of disablement in this region and fills a gap in the literature on this subject.

Regional conditions in the natural environment like heavy snowfall combined with the absence of accessible transportation, poor road conditions and snow-covered ramps prevent community participation for all individuals with disabilities. Similarly, community specific factors in the social environment such as positive attitudes towards people with disabilities combined with maintenance of the Inuit cultural value of sharing are examples of conditions that facilitate participation.

The health status of Inuit communities has been analyzed and researchers have found that chronic disease is on the rise (Anand, 2001; Bjerregaard & Young, 1998; Bjerregard, 2001; Peschken & Esdaile, 1999; Rode and Shephard, 1995). Researchers, colleagues and Northern residents often attempt to make a direct link between a high level of disablement and disease etiology. Although individual impairment should not be entirely excluded from discussion about disablement in the Baffin Region, a single focus on this precludes a collective, community perspective on the issue (Priestley, 1998).

However, the results of this study indicate that analysis of the social and physical environments combined with careful consideration of cultural values create a cohesive perspective on disablement in the Baffin Region. This is consistent with Occupational Therapy Theory and Cross-Cultural disability studies (Dunn et al, 1994; Grady, 1995; Ingstad & Whyte, 1995; Ingstad, 1990; Kasonde-Ng'andu, 1998; Kielhofner, 2002; Law, 1991; Mosey, 1998; Pal et al, 2002; Rebeiro, 2001; Rosing, 1999).

Most Needs Assessments to date in Arctic Canada emphasize enhanced health service provision in itself as a viable solution to a high incidence of disablement. (Fricke, 1999; Rokash, 2002; Lutra Associates Ltd, 2000; T-Base Research & Development Inc., 1998; University of Manitoba, 2003; Watts, 1998.) Despite the valuable contribution of this work,

it offers an incomplete foundation from which to initiate CBR programs in this region. The main reason for this is the noticeable absence of input from Inuit with disabilities, community members, and caregivers.

The participation of community members in the planning stages is critical to the long-term sustainability of any Community-based Rehabilitation program (Boyce, 2000; Price & Kuipers, 2000). The interpretation of suggestions from the communities offers a more holistic foundation for initiating CBR Programs in the Baffin Region of Nunavut and in other Arctic Canadian regions.

8.4.2 Community-based Rehabilitation – A Viable Model for Enhancing Participation

Community-based Rehabilitation is defined as a strategy within community development for the rehabilitation equalization of opportunities and social integration of all people with disabilities (WHO, 1996). CBR is an appropriate model for program development in Arctic regions as it encompasses the holistic nature of factors influencing disability and addresses removal of barriers to community participation.

Suggestions from participants have been combined with the researchers interpretations in order to create a brief outline a model for CBR in Canadian Arctic regions. Furthermore, research on sustainable program development emphasizes that identifying, mobilizing and sustaining existing community resources is one important tenet of a successful rural health program (Government of Nunavut, 2003; Kretzmann & McKnight; Troughton, 1999; WHO, 1996). There are many organizations, services and committees in the North which can serve as strengths to build upon in a CBR program. An example of community organizations in the Baffin Region (Table 12) demonstrates the type of resources that may exist in Arctic communities.

Table 12: Baffin Region Community Resources

Resource Category	Iqaluit	Pangnirtung	Pond Inlet
Health Systems	**Iqaluit Homecare** **Hospital** **Public Health**	**Health Centre** **Pangnirtung Homecare**	**Health Centre** **Pond Inlet Homecare**
Government & Community Organizations	**Iqaluit Town Council** **Nunavut Territorial Government** **Inuit Organizations** **NTI** **QIA** **Housing Association**	**Pangnirtung Hamlet** **Community Wellness Committee** **Hunters and Trappers Association** **Housing Association**	**Pond Inlet Hamlet** **Community Wellness Committee** **Hunters and Trappers Association** **Housing Association**
Other Community Resources:	**Arctic College** **Library** **Food bank** **Help line** **Women's Shelter**	**Uqqurmuit Arts and Crafts Centre** **Library** **Arctic College**	**Library** **Arctic College**

In addition to the utilization of existing resources, the following principles are important in a community based rehabilitation program: transfer of knowledge about disabilities and skills in rehabilitation to people with disabilities, families and communities; community involvement in planning, decision making and evaluation; utilization and strengthening of referral services across all levels; and utilization of a co-ordinated, multi-sector approach (Mitchell, 1999). This is an appropriate strategy for program development in the Baffin Region and other Arctic communities as it places an emphasis on overcoming barriers. With these principles in mind, combined with categories of community resources listed above, and interpretation of research results found in chapters six and seven, a model for a knowledge based approach to CBR in arctic regions of Canada is suggested (Figure 7).

Three hierarchical levels of organization are typically involved in a CBR program: Central (Ministry of Health or Federal), District (Territory or Province) and Community

(Health workers, people with disabilities, family ect.) (Mitchell, 1999). Communty-based Rehabilitation starts at the national level with a plan for medical rehabilitation. This plan is then channelled to the district and community level. A more lateral approach between these three levels of stakeholders may foster greater participation from the communities involved. As such, it is recommended that a representative from the community hamlets, from the government and from Inuit/Aboriginal organizations develop a working group and liase together throughout the project. In this way, they can take responsibility for the project, and generate and disseminate knowledge.

The establishment of a regional disability council through a local Inuit/Aboriginal organization will provide sustainability for CBR programs. This council would educate, advocate, counsel and assess needs on a continuing basis. This council would interact with health services and with community representatives to continuously address the changing needs of individuals with disabilities in each community. On-going funding to Inuit/Aboriginal organizations may be an area to explore during the planning stages of a CBR program.

The disability council could also collaborate with the government and with regional health, education and labour representatives to pool existing resources. The council could organize workshops to transfer the following community and region specific skill and knowledge set: knowledge related to rehabilitation and disability, skills related to rehabilitation and disability and multi-sector education. The transfer of this knowledge should be based on the results of community research. It is evident from this study that communities have unique needs despite their regional homogeneity.

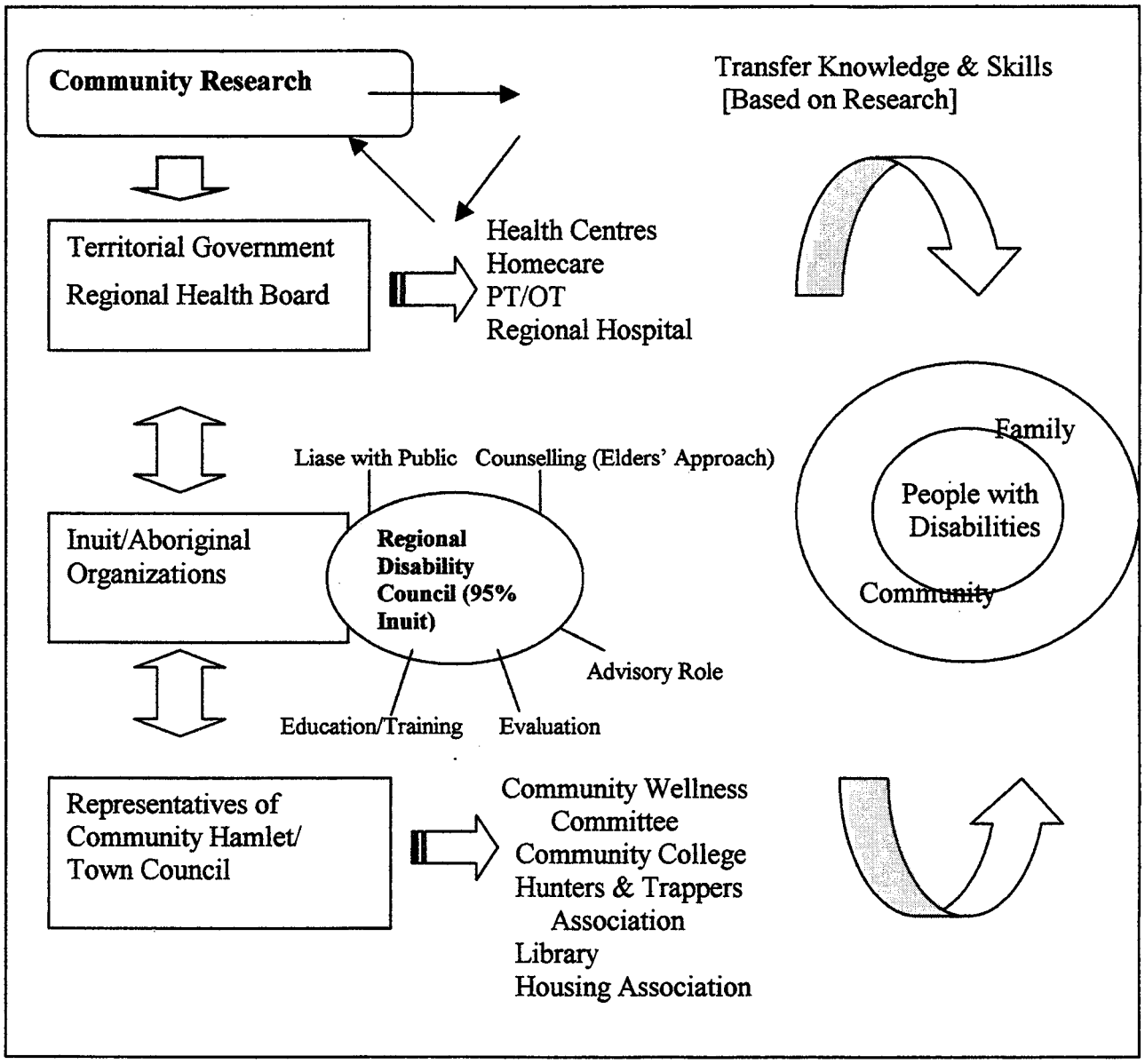

Figure 7: Model for CBR in the Canadian Arctic

The following table (13) is an example of how unique community variations identified through this research may alter the content of knowledge, skills and multi-sector education transferred to community resources in a CBR program in the Baffin Region. For example, individuals in Pangnirtung felt that they would benefit from rehabilitation skills and services whereas individuals in Pond Inlet expressed the need for counselling skills. As such, a unique approach to skill transfer in these two communities based on expressed deficiencies would

most effectively target the need. This emphasizes the importance of research in the planning stages of CBR programs in Arctic Canada.

Table 13: Community variations and CBR content.

	Iqaluit	Pangnirtung	Pond Inlet
Skills	**Prescription and System for Obtaining Equipment.** **Counselling**	**Prescription and System for Obtaining Equipment** **Rehabilitation: Pain Relief & Exercise**	**Counselling people with disabilities.** **Obtaining Equipment for individuals with COPD.**
Knowledge	**Political advocacy for physical accessibility.**	**Disability and the environment.**	**Rehabilitation Therapy** **The purpose of Homecare**
Multi-Sector Education	**Accessibility** **Transportation** **Enhancing Vocational opportunities for people with disabilities.**	**Accessibility** **Transportation**	**General Disability Education** **Transportation.** **Land initiatives for people with disabilities.** **People with disabilities getting food.**

When is comes to general considerations about development, it is important to consider that development in Nunavut may not resemble development in Southern Ontario. The words of a long time resident in the Baffin Region clearly outline this reality:

> Development is like pushing a rope, it takes forever for it to happen. In Southern Canada you are dealing with people that have been in the business for a long time and the infrastructure and training is there so you can see immediate results. The challenge here in the North is that it takes a lot longer.

For this reason, it is important that time is taken in the early stages of CBR development in Arctic Canada to understand community perspectives through research. This will ensure that the program delivered is addressing the diverse needs of people with disabilities and that it has the capacity to enhance participation for them. Furthermore, early planning and research will identify resources and strengths to build upon so that execution and continued evaluation of CBR programs will continue in a sustainable way for many years into the future.

Chapter 9

Summary and Conclusions

9.1 Contributions

1. The naturalistic study of disablement in this Arctic region of Canada has contributed to the body of academic knowledge on this subject in the field of rehabilitation therapy. It has integrated contextual community descriptions into disability experiences in order to generate a comprehensive perspective on facilitators and barriers to community participation for Inuit with disabilities. In doing so, this research has obtained a holistic, culturally relevant community perspective instead of a traditional impairment focused perspective on disablement. The comparison of Iqaluit, Pangnirtung and Pond Inlet also highlights that disability is inextricably linked to the unique social and physical fabric of each community. This research demonstrates the importance of community-based analysis of factors influencing disablement as a precursor to development of Health Programs.
2. The participatory nature of this study has, in itself, generated discussion in Baffin communities about perceived barriers to community participation. Participant collaboration through focus group interaction in order to develop suggestions for future action was a significant step toward community empowerment. This may motivate communities to take action and work together to enhance participation for individuals with disabilities. The incorporation of suggestions from community members into interpretations of facilitators and barriers and existing research has allowed a hypothetical model for Community-based Rehabilitation in this region to be developed. This model may be applicable to other northern regions of Canada.

3. Collaboration on this research with partners in Nunavut (Qiqiqtani Inuit Association, Community Hamlet Representatives, and the Government of Nunavut) has also generated discussion on this topic. Transfer of research knowledge to and from these regional and community partners will increase the likelihood of continued discussion and generation of CBR initiatives in the Baffin Region.

9.2 Strengths and Limitations

9.2.1 Strengths

To the author's knowledge, this is the first ethnographic study of disablement in a remote Arctic region. Familiarity with the region and time spent embedded in the Baffin Island context allowed the researcher to obtain an emic or insider perspective of the environmental factors that contribute to disablement here. Member checks, expert checks, an interim report and reflexive journaling took place throughout the study in order to verify the researcher's interpretations of the findings. Triangulation of data sources and methods also contributed to the trustworthiness of this study as concepts were compared for consistency. A pilot focus group also took place to ensure that the protocol was accurately addressing the research questions.

This study was implemented in ways that were sensitive to the nature of human, cultural and social contexts. A high degree of participation through focus group interaction and member checking took place. This seemed to evoke a sense of empowerment from participants as Inuit with disabilities shared their stories and generated ideas for solutions. Input was sought throughout the study from community leaders and from Inuit organizations. This is the first step in a developmental process of CBR in the Baffin Region. A CBR

program would closely reflect the expressed needs of people with disabilities living in the Baffin Region if implemented based on these findings.

Explicit description of personal background, disability theory framework and research paradigm were described in the first three chapters. This enhances credibility and exposes researcher bias that may affect the interpretation of the data. This study demonstrates congruence between the research question, methods and findings, between the current study and the body of literature and between these findings and practical ideas for program development. In essence, it fits into a context outside this particular situation.

9.2.2 Limitations

A greater amount of time spent in the field would have allowed for more thorough exploration of the research questions and greater development of ideas. A more participatory approach would also have been ideal but due to limited program resources and time, this was not possible. Participation of a greater number and diversity of individuals with disabilities also would have allowed more complete answers to the research questions. This concept is referred to as saturation.

The researcher also worked as a physiotherapist while conducting this study. Although an attempt was made to refrain from providing clinical advice or guidance to study participants, the knowledge of this position alone could have impacted disclosure of medically based needs. Furthermore, the researcher explicitly acknowledged a bias toward the social frame of reference for the study. This may have had an impact on revelations related to impairments or medical rehabilitation needs.

It is possible that changes in meaning occurred during translation. Local interpreters were used in each community. This minimized the likelihood of misinterpretation due to variations in dialect. On site, simultaneous translators were used which Esposito (2001) recommends in her article on the Influence of Translation Techniques on Non-English Focus Group Research. Despite these provisions, back translation of the original transcripts into Inuktitut and comparison with the real time English translation was impossible due to time and budget constraints.

9.3 Recommendations for Future Research

1. Demographic heterogeneity and the acculturation process happening there may impact the degree of isolation and paid work opportunities experienced by women with disabilities. This is consistent with the research base on women with disabilities that emphasizes the oppression of this group. Further qualitative action research that explores barriers to employment for Inuit women with disabilities may be an area for future investigation.
2. The relatively low socio-economic status of a community may have an impact on informal support systems, thus influencing the degree of participation for individuals with disabilities. Acculturation stress may also provide an explanation for some conflict in families regarding traditionally female assigned, care-giving roles and the impact that decreased land activities has on elders with disabilities. Further qualitative investigation exploring the phenomenon of acculturation stress as it affects the well-being of individuals with disabilities living in this region may provide a more in depth perspective on social barriers to community participation.

3. Physical accessibility and transportation are widespread obstacles for individuals with disabilities, particularly for individuals living in rural areas. Nunavutmiut with disabilities feel absence of transportation severely limits their ability to participate in community life. Further, more focused investigation into factors in the physical environment that limit community participation in various Arctic regions and the policies that impact these barriers is needed.
4. Participatory Action Research that focuses on community members of remote Arctic communities assessing their own needs in the area of disability is a focus for future research. This would create a comprehensive perspective and relevant foundation for development and evaluation of CBR in Arctic Canada.

9.4 Conclusion

The holistic nature of this study prioritizes the contextual stories of Inuit with disabilities in order to illuminate a much needed social perspective on this subject. This is a new perspective from which to describe disablement in Arctic Canada. From this research, it is apparent that there are many factors in the social and physical environments that affect participation in these three Baffin Island communities.

Universal barriers exist for Inuit with disabilities across the region but the conditions of Iqaluit, Pangnirtung, and Pond Inlet are distinct. Common characteristics of the physical environment such as rugged terrain, harsh climate and poor infrastructure limit participation for individuals with disabilities. In Iqaluit and Pond Inlet, it appears that there is a sense of isolation derived from a relative lack of informal support and from negative community attitudes. The cohesive nature of the community of Pangnirtung fosters an inclusive attitude toward people with disabilities.

An evolving process of acculturation, variations in socio-economic status, heterogeneity of the community and gender all impact the degree of participation experienced by individuals in Arctic regions of Canada. These factors in the social environment may prove to be more relevant than impairment related data in a medical context when attempting to create programs geared to suit the needs of entire Arctic communities.

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Appendix A

Nunavut Research Institute License
Queen's University Ethics Approval

Nunavummi Qaujisaqtulirijikkut / Nunavut Research Institute
Box 1720, Iqaluit, NU X0A 0H0 phone:(867) 979-4108 fax: (867) 979-4681 e-mail: slcnri@nunanet.com

January 10, 2003

NOTIFICATION OF RESEARCH

PLEASE BE ADVISED THAT SCIENCE RESEARCH LICENCE No. 0500303N-M HAS BEEN ISSUED TO:

Jill Robison
Baffin Regional Physiotherapist
P.O. Box 6000, Station 1038
Iqaluit, Nunavut
X0A 0H0
867-975-4819

TO CONDUCT THE FOLLOWING STUDY:
Baffin Island Disablement Study

SUMMARY OF RESEARCH:
National and regional studies show that Inuit and aboriginal Canadians experience higher levels of disablement than non-aboriginal Canadians. However, qualitative methodology has rarely been used to explore the impact of this discrepancy. This project will use qualitative methods in order to understand the impact of disability on community participation in the Baffin region. The aims are to understand, from the perspective of Inuit people, what constitutes disablement, what affects community participation, and what Inuit feel would help people with disabilities in the future. Focus groups and interviews will take place in three of ten Baffin communities. Qualitative content analysis will be used to obtain rich descriptions of Inuit experience. Ongoing communicatin and feedback from local health councils, will take place. Recommendations will be provided to communitiy representatives, to the department of Health and Social Services and to the Qikiqtani Inuit Association. This information will help with a collaborative effort to develop sustainable community based rehabilitation programs in the future.

THE STUDY WILL BE CONDUCTED AT: Iqaluit, Pond Inlet, Pangnirtung
BETWEEN: October 1, 2002 - April 30, 2003

Mary Ellen Thomas
Manager, Research Liaison

DISTRIBUTION:
Social Policy Analyst, NTI, Social & Cultural Development Dept
Lands Administrator, QIA
Director, Policy and Planning, H & SS
Mayor/SAO, Municipality of Pangnirtung
Mayor/SAO, Municipality of Pond Inlet
Mayor/SAO, City of Iqaluit

QUEEN'S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING HOSPITALS RESEARCH ETHICS BOARD

Queen's University

Queen's University, in accordance with the "Tri-Council Policy Statement, 1998" prepared by the Medical Research Council, Natural Sciences and Engineering Research Council of Canada and Social Sciences and Humanities Research Council of Canada requires that research projects involving human subjects be reviewed annually to determine their acceptability on ethical grounds.

A Research Ethics Board composed of:

Dr. A.F. Clark	**Head and Professor, Department of Biochemistry, Professor, Department of Pathology, Faculty of Health Sciences, Queen's University (Chair)**
Dr. S. Burke	**Professor, School of Nursing, Queen's University**
Dr. I. Casson	**Assistant Professor, Department of Family Medicine, Queen's University**
Rev. T. Deline	**Community Member**
Dr. D. Holland	**Assistant Professor, Department of Medicine, Division of Nephrology, Queen's University**
Mr. C. Kenny	**Community Member**
Ms. C. Lyle	**Clinical Nurse Specialist, Providence Continuing Care Centre (St. Mary's of the Lake Hospital Site)**
Dr. J. Low	**Professor, Department of Obstetrics and Gynaecology, Queen's University and Kingston General Hospital**
Ms. P. Peppin	**Associate Professor, Faculty of Law and Assistant Professor, Department of Family Medicine, Queen's University**
Dr. W. Racz	**Professor, Department of Pharmacology & Toxicology, Queen's University**
Dr. J. Rapin	**Assistant Professor, Department of Emergency Medicine, Queen's University**
Dr. L. Seymour	**Co-Director, IND Program, NCIC Clinical Trials Group Associate Professor, Department of Oncology, Queen's University**
Dr. A.N. Singh	**WHO Professor in Psychosomatic Medicine and Psychopharmacology Professor of Psychiatry and Pharmacology Chair and Head, Division of Psychopharmacology, Queen's University**
Dr. S.J. Taylor	**Director, Office of Bioethics, Queen's University and Kingston General Hospital; Associate Professor, Department of Medicine, Queen's University**
Dr. G. Torrible	**Community Member**

has examined the protocol and revised consent form for the project entitled **"Baffin Island Disablement Study"** as proposed by Ms. J. Robison, Dr. Sandra Olney and Dr. Will Boyce of the School of Rehabilitation Therapy at Queen's University and considers it to be ethically acceptable. This approval is valid for one year. If there are any amendments or changes to the protocol affecting the subjects in this study, it is the responsibility of the principal investigator to notify the Research Ethics Board. Any adverse events must be reported to the Chair within 48 hours.

____ _____ Oct 17, 2002

Chair, Research Ethics Board Date

ORIGINAL TO INVESTIGATOR - COPY TO DEPARTMENT HEAD- COPY TO HOSPITAL(S) - P&T - FILE COPY

REH-165-02
2002-09-09

Appendix B

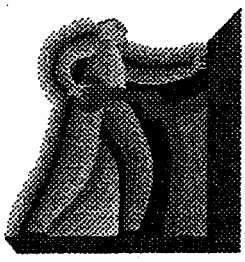
Sampling: Example of Radio Announcement and Posted Advertisement

Baffin Island Disablement Project.

You are invited to attend a group meeting to participate in a research project on disability in your community.

When: Thursday Feb. 6, 2003

Time: 6-7:30 pm



Where: Pond Inlet Health Centre

Refreshments and Transportation will be provided.

The goals of this meeting are:

- To understand what disability means for Inuit people
- To understand what helps/prevents Inuit people with disabilities participate in community activities
- To understand what kinds of services Inuit people think would be good for people with disabilities

Your participation will create the knowledge needed to create programs for people with disabilities in the future. I hope to take this information and work with health and social services, QIA and community members to create culturally appropriate community based rehabilitation programming. No immediate benefits will take place in terms of equipment, services, or programs.

Please contact to confirm your attendance.

Pond Inlet Health Centre 867– 8990-8840
Jill Robison 867-975-4819 OR 867-975-4800

CBC Radio Public Service Announcement

From: Jill Robison
Date: Dec. 6, 2002
Phone: In Iqaluit: 867-975-4800

Re: Baffin Disability Study

Are you a person with a disability, a caregiver or family member of a person with a disability in Iqaluit? If so, you are invited to participate in a research project on disability in the Baffin Region.

This will take place on Dec. 14 at the Pangnirtung Health Centre from 5:00 pm to 6:30 pm. Refreshments will be provided.

The goals of this meeting are to :

To Understand what disability means for Inuit.
To Understand what helps or prevents Inuit with disabilities from participating in community activities.
To Think about what we can do in the future to help spread awareness and improve life for Inuit with disabilities.

Your participation will help create the knowledge needed to create programs in the future for people with disabilities. This information will be used to work with health and social services, Inuit organizations, and community members to create community based programs. **No immediate** benefits will take place in terms of equipment, services or programs.

If you would like to participate in this project.

Please call 867-975-4800 for more information or to confirm attendance.

This focus group will take place on Saturday Dec. 14 at the Pangnirtung Health Centre from 5:00 – 6:30.

Appendix C

Consent Form and Confidentiality Agreement

Consent Form - Also in Inuktitut

You are invited to volunteer your time to participate in research on:

The impact of disability on community participation in the Baffin Region

A large number of Inuit people live with a disability. More Inuit people have disabilities than the average Canadian person. Learning about disability in Baffin communities may help the future for Inuit people with disabilities.

The aims of this study are to:

- Understand what disability means for Inuit people living in Baffin Island communities.
- Understand what helps/prevents Inuit people with disabilities from participating in community activities.
- Understand what kinds of services Inuit people think would be good for people with disabilities.

Understanding of disability will be increased for the following groups:

- Qikiqtani Inuit Association
- Baffin Department of Health and Social Services
- Community Health Councils
- Families, community members, and people with disabilities

You are invited to:

A) Take part in group discussions

You will be asked questions, and asked to draw pictures. The group will last 90 minutes. The session will be recorded. Examples of group activities:

- Draw a picture of yourself.
- What happens on a journey to the flow edge?
- Together, draw a picture of your community.
- If a rock is a barrier what rocks exist in your community?
- What animal do you represent and why?

And/or

B) Take part in an interview

You will be asked questions. It will last 60 minutes. The interview will be recorded. Examples of questions:

- What Illiqqusiq (traditional ways, habits) are important to you?
- Are there people who help you?
- What is your role in the community?

Benefits/Risks

There are no direct benefits if you participate in this study: No services, equipment, programs or opportunities will directly result from your participation. Your participation will create new knowledge about disability issues for Inuit people. This knowledge may contribute to programs to help people with disabilities in your community in the future.

Benefits/Risks cont'd

A possible risk is the stressful emotions you may feel after expressing feelings about disability. You are free to refuse to answer any question that may be too emotional.

Distribution of Information

All information will be confidential. Your identity will not be revealed in any published findings. The information from the study will be distributed to your local community hamlet representative, the local health centres, to the director of Health and Social Services and to the Quikiqtani Inuit Association.

Study Contacts & Funding

This study is being conducted by Jill Robison, MSc candidate, School of Rehabilitation Therapy, Queen's University, Canada. This study will be supervised by Dr. William Boyce of Queen's University. This study is partially funded by the Northern Scientific Training Program through the department of Indian Affairs and Northern Development. It has been approved by the Nunavut Department of Health and Social Services, The Nunavut Research Institute, the Quikiqtani Inuit Association and Community Hamlet representatives.

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Dr. Albert Clark
Chair Research Ethics Board, Faculty of Health Sciences, Queen's University
1-613-533-6081

Nunavut Research Institute:
867-979-4115

Qikiqtani Inuit Association – Health Liaison officer
867-979-5391

Pangnirtung Community Hamlet Representative
867-473-8953

Pond Inlet Community Hamlet Representative
867-899-8934

SUBJECT STATEMENT

Do you agree to participate in this study? Yes/No

_____ _____

Signature Date

STATEMENT OF INVESTIGATOR

I have explained the subject the nature of the research study and certify that to the best of my knowledge, the subject understand the benefits and risks involved to participants in this study. A copy of this consent form will be provided to each subject.

_____ _____

Signature of Principal Investigator Date

Confidentiality Agreement

You are invited to work as an interpreter in a research study on:

The impact of disability on community participation in the Baffin Region.

This study is being conducted by Jill Robison, MSc candidate, School of Rehabilitation Therapy, Queen's University, Ontario Canada. It is partially funded by the Northern Scientific Training Program through the Canadian Department of Indian Affairs and Northern Development.

Your task will involve the translation from Inuktitut to English of the interviews and assistance with and/or transcription of those interviews in English.

The names of all people who participate mush remain confidential and the content of the interview mush not be disclosed.

Your discretion and respect of people's confidentiality is essential.

- ☐ I understand what has been explained to me
- ☐ I will not disclose the name or identity of a participant in an interview
- ☐ I will not disclose the content of the discussion

_____ _____

Signature of the interpreter Date

_____ _____

Signature of the researcher Date

Appendix D

Focus Group and Interview Protocols

Focus Group Protocol

Time 1.5-2 hours with one 15 minute break: Refreshments Provided
Number: 4-7 participants + 1 interpreter + 1 moderator (primary researcher)
Recording: Jotted Field Notes/Audio recording

Introduction to self and to experience with disability.

My name is Jill Robison. I am from Kingston, Ontario. Graduated from University five years ago. I am now a physiotherapist working at in Iqaluit. I am also doing research for my Masters degree on disability in this region. I lived here for one year 1999-2000 and realized that many people had disabilities and in general there is not a lot of knowledge about the needs of people with disabilities. That is why I chose to do this project on disability. This research project includes people in the Baffin Region who have experience with disability. All of the people here tonight have experience with disability. The main purpose of this project is to increase knowledge and understanding for community members, for Inuit organizations, for the Department of Health and Social Services and for each individual community hamlet. The goals are to find out what things help people with disabilities and what things stop people with disabilities from doing activities. Another goal is to understand how Inuit feel about disability. The last goal is to create recommendations for future programs and services. Tonight we will be getting to know one another by sharing ideas and stories. This will help create knowledge about disability.

Framework of questions used to facilitate focus group discussion.

1.	**From birth until now who, what places, and what activities are most important to you. Imagine that you are filling in the chunks of an igloo with these things.** **Probes Inuit Culture?** **[Diagram of white igloo held up as point of reference]**	**Objective I** Establishes type & degree of participation. Identifies type of participation. Creates context for person with disability, caregiver or family member.
2.	**What are some things that help people with disabilities to participate in the community?** **[Use examples of activities described in 1]**	**Objective II** Identifies facilitators to participation.
3.	**On the other hand, what things in your community make .... more difficult for people with disabilities to participate?** **[Use examples of activities described in 1]**	**Objective II** Identifies barriers to participation.
4.	**Where should we go from here? What do you see in the future for Inuit with disabilities?**	**Objective III.** **Identifies suggestions for future action from participants.**

Interview Protocols

30-60 minutes Recording: Jotted Notes/Audio-Recording Location: Chosen by Participant

Caregivers

1. What experience do you have with disability.
    a. Probes: Work, family, length of time in position.
2. If family member, question length of time with disability, and type of disability.
3. What types of activities would people with disabilities participate in?
4. What makes life easier for people with disabilities?
5. What makes it difficult for people with disabilities to participate in the community?
6. Close your eyes and envision a particularly difficult experience you have had with a person with a disability . . . tell me about that time.
7. On the other hand, is there a time when things were really good? . You had a good experience with someone with a disability. Teel me about that time.
8. How do you think we can move forward in the future. Where can we go from here to assist people with disabilities?

Community Members – Health Professionals

1. What is your position?
2. How long have you been in this position?
3. What types of clients to you and your staff typically see?
    a. Do any of these people have physical disabilities?
    b. What role does _____ have in assisting people with physical disabilities?
4. Can you think of a specific interaction you have had with a person with a physical Disability that stands out in your mind?
    a. Probe – Something that surprised you?
5. In focus group meetings we have talked a little bit about the role that families play in assisting people with physical disabilities.
    a. Where do you see the place of family for Inuit with disabilities?
    b. What would it be like if someone didn't have family?
6. In an ideal world and drawing on your own experience, what would help people with disabilities living in _____ feel like part of the community.

Probe – Activities, Services, Attitudes?

Appendix E

Disability Board Positions, Responsibilities and Salaries

Disability Board Proposal: Positions, Responsibilities and Salaries. (Adapted from Anita's Advocacy Document)

Position	Responsibilities	Salary
Manager/Chairperson	Communication between board and public. Administrative details. Monitors budget & related correspondence. Computer use and duties recommended by the board.	$ 25 000
Counsellor/Secretary	Recording meetings, typing all & filing. Home-visiting to board and to disabled people. Fulfilling concerns of board members.	$ 23 000
Transportation & Hotels	Booking conferences and meetings.	$ 1 000
Capital/Budget	Invoices that go in and out. Capital and administrative needs, salaries, honorariums. Daily and monthly balancing of bank statement.	$ 1 000
Town Council and/or Government Liaison	Communicating minutes to public.	$ 1 000
Training and Education	Co-ordinating education and training sessions Contracting government workers if necessary.	$ 1 000

Appendix F

Counseling Strategy for People with Disabilities

Counselling Strategy for People with Disabilities (Adapted from Anita's Advocacy Document)