

**CREATING A REGISTRY OF NEEDS FOR PERSONS WITH  
DISABILITIES IN A NORTHERN CANADIAN COMMUNITY –  
THE DISABILITY REGISTRY PROJECT**

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***ABSTRACT***

*This study was designed to explore barriers impacting activities and participation of persons with disabilities in a northern Canadian aboriginal community, and to create a communication and documentation system for health professionals in the community to be able to track and address such factors. This report summarises barriers reported by participants.*

**INTRODUCTION**

Persons with disabilities living in the catchment area of the Weeneebayko Health Ahtuskaywin (WHA), a self-governing Aboriginal Cree Mushkegowuk Territory health board responsible for health services for the West coast of James Bay, have identified concerns with accessibility to appropriate health care and services (1, 2). Persons with disabilities reported a sense of helplessness, and were uncertain how to access appropriate health professionals when they encountered difficulties related to their impairments. According to Robarts (1), persons with disabilities should be the ones who are most able to identify their needs, and outline their individual needs, in order to advocate for improved services through community leaders.

A previous community based rehabilitation (CBR) project attempted to address some gaps in access to rehabilitation by training community rehabilitation aides (3). However, because the infrastructure to employ these persons was missing, such training did not lead to systemic changes. Moose Factory is a community of approximately 2700 persons (4). There are more off-reserve than on-reserve Moose Cree members.

Concepts of CBR include effectiveness and sustainability in the provision of care to persons with disabilities (5). In a community such as Moose Factory, which has a local hospital that serves the region, the goal would be to encourage awareness in local health care professionals and community leaders of the needs of persons with disabilities, and challenges that they face, in order to facilitate their community participation. The International Classification of

Functioning, Disability and Health (ICF), (6) provides a framework for understanding the general relationships between health and functioning. Participation is defined by the ICF as “involvement in a life situation.” Examples of participation include volunteering, participating in community events, engaging in advocacy work, parenting a child, and working at a job. In the conceptual framework described in ICF, problems in body structures and functions, otherwise known as “impairments,” inter-relate with activities and participation through personal and environmental factors. Identification of modifiable factors is key to facilitating participation in persons with disabilities.

Lack of appropriate follow-up was a previously identified area of concern (1). If a registry is successfully implemented and managed, individual persons could be connected with the appropriate health care professionals in their community, and appropriate services to access could be identified. Their needs would be known, and follow-through would be more likely. The family medicine department, based in the Weeneebayko General Hospital (WGH) in Moose Factory, is funded by the WHA. It provides comprehensive health care for approximately 11,300 Cree residents in six communities: Moosonee, Fort Albany, Kashechewan, Attawapiskat, Peawanuck, and Moose Factory. Other institutions in the area include James Bay General Hospital (sites in Moosonee, Fort Albany, and Attawapiskat) and the Federal Nursing Stations of Kashechewan and Peawanuck (7). There is a Physical Therapy department in the WGH that also serves these communities. It would be appropriate for the Family Medicine and Physical Therapy departments to have access to such a registry. Additionally, access by community health nurses might be beneficial. It could indicate duration of time between identification of rehabilitation needs and attainment of appropriate modifications or management. A registry could also allow analysis of common barriers. If enough common needs are identified collectively, such information could be used by community leaders to determine priorities and funding allocation. Support for ongoing management and updating of the registry by users and the WHA would be required for the registry to be practically useful for health care providers in the area.

### **Background of project**

This project started as a result of a pivotal meeting in July 2003, attended by a former family physician at WGH, a physiotherapist at WGH, community leaders in Moose Factory including

the former, and now re-elected Chief and current Health Director of the Moose Cree Nation and a representative member of the Mo Creebec Nation, and the author, a specialist in Physical Medicine and Rehabilitation at Queen's University. The Chief had indicated that if there were data to support community improvements that might improve the lives of persons with disabilities, such information would be considered in community planning. After meeting with the Mushkegowuk Council's Health and Social Services Planner, who indicated a need for data to support development of funding proposals for health and social services, a letter of support for the project was provided through the Chief Executive Officer of WHA. A proposal for the development of a Disability Registry, initially intended for all six communities of the WHA, was drafted with the input of the research director of the time, and ethics approvals were obtained from Queen's University (October 2003) and the WHA (December 2003).

Directions as provided by the WHA research director were then followed: letters were written to the health directors of each First Nation to determine interest in participation in the project. Several inquiries were made to non-responders. Positive responses were obtained from two communities, and approval was provided by the Moose Cree Nation in Moose Factory January 2004. Fort Albany also indicated interest, but did not indicate that processes for approval were satisfied until January 2007. Efforts were then made to connect with local persons identified by health directors, for the purposes of informing persons with disabilities about the project.

## **METHOD**

Information about the registry was posted in the Wawatay newspaper and television channel, as well as at the Weeneebayko General Hospital (WGH) and Health Post in Moose Factory. People who were interested contacted a designated person to fill out a consent to release their contact information to the primary investigator, or they had the option of direct contact with the primary investigator.

Data were collected on-site during the month of June 2008. Twenty-one participants with disability were interviewed, 20 from the community of Moose Factory, and 1 living in Timmins, Ontario, who self-identified as being of the Moose Cree band, Mo Creebec nation, or a community member. The individual in Timmins was interviewed by telephone, and the others

in person, either at their homes, or at the WGH, according to their preferences. Individual impairments and needs were collected and entered into a database; this information was provided to the medical records department, physical therapy department, and research director at the WGH. The intent was for database information to be formatted into a usable format by the WGH, accessed, and added to by health professionals working with persons with disabilities in Moose Factory.

In addition to individualised data, suggestions to facilitate community participation of persons with disabilities were elicited from participants, and are presented in this report. Also, persons involved in health care provision in the WHA shared the realities and challenges in providing care in the region. These observations were recorded and summarised. This report provides collated information on the entire group of participants, identifying collective needs and suggestions. 21 participants signed consent forms and participated in interviews. Almost all were of aboriginal affiliation. Each was scored on the Barthel Index (BI, 8) and Participation Scale (P-Scale, 9), which measure activities of daily living and participation, respectively.

## **RESULTS**

Average age of participants was  $65.9 \pm 13.7$  years. Five individuals lived alone, two in an Elders' apartment, and 14 with family. Average BI score was  $83.6 \pm 22$  (range 15-100). Eight persons scored 100 on the BI, being completely independent in activities of daily living. Average P-scale score was  $21.8 \pm 12.4$ . With respect to impairments, categories from the International Classification of Functioning, Disability and Health (6) were used.

Numbers of persons with individual impairments are shown in Table 1. Musculoskeletal conditions were the most frequent, causing some degree of pain and disability in about half the participants. Approximately half the participants had difficulties related to diabetes, and half had visual impairments. Average age of participants with musculoskeletal impairments, diabetes, or visual impairments were similar, ranging from 67 years to 67.9 years. However, when one looked at the severity of impairments, those with severe impairments related to diabetes were younger (average 61 years) than for musculoskeletal (average 62.5 years) or visual (average 67.3 years) impairments.

**Table 1. Numbers of participants with specific impairments**

Area of Impairment	ICF code	Number of Participants with impairment (%)	Participants with large or total difficulty with impairment
Thinking	b144,160,164	7 (33)	1
Learning	d155	1 (5)	0
Paying attention	d160	3 (14)	0
Calculating	d172	1 (5)	0
Focusing on >1 activity	d220	5 (24)	1
Managing stress	d240	5 (24)	2
Reading/Writing	d166, d170	6 (29)	2
Comprehension	d310, d315	2 (10)	1
Speaking	d330, d350	1 (5)	1
Sight	b210	10 (48)	3
Taste/Smell	b250, b255	2 (10)	1
Touch	b265	6 (29)	3
Pain	b280	11 (52)	3
Vocal production	b310	2 (10)	0
Musculoskeletal difficulty	b710, b715, b720, b729, b730, b740	15 (71)	6
Movement	b755, b760	2 (10)	2
Changing position	d410	2 (10)	1
Maintaining posture	d415	2 (10)	1
Lifting	d430	14 (67)	5
Using fingers	d440	7 (33)	2
Using hands/arms	d445	9 (43)	2
Immunity	b435	3 (14)	0
Temperature regulation	b550	10 (48)	3
Sleep	b134	6 (29)	2
Breathing	b440	6 (29)	1

Blood pressure	b420	8 (38)	0
Heart	b410	5 (24)	0
Gastrointestinal	b515, b525	9 (43)	1
Genitourinary	b610, b620, b640, b650	5 (24)	2
Diabetes	b555	10 (48)	5

Numbers of persons reporting difficulties in specific aspects of participation are presented in Table 2. Barriers to participation are shown in Table 3. Twelve of the 21 reported being about to get out of their homes as often as they would like. With respect to quality of life, on an average, they rated it as rather neutral (0.6 on a scale of -10 to +10, SD 4.9), neither good, nor bad.

**Table 2. Numbers of participants reporting difficulties**

Activity/Role	ICF code	Number of participants reporting difficulty (%)	Number reporting large or total difficulty
Using transportation	d470	13 (62)	1
Driving	d475	5 (24; N/A for 13)	3
Taking care of health	d570	11 (52)	5
Finding accommodations	d610	6 (29)	1
Getting help/food/services	d620	5 (24)	2
Preparing meals	d630	15 (71)	4
Helping	d660	5 (24)	1
Relating with family	d760	3 (14)	1
Relating with strangers	d730	4 (19)	0
Intimate relationships	d770	3 (14; N/A for 12)	2
Informal relationships	d750	9 (43)	3
Work training	d840	8 (38; N/A for 11)	4

Getting a job	d845, d850	8 (38; N/A for 11)	4
Volunteering	d855	3 (14; N/A for 1)	0
Financial management	d860, d865	5 (24; N/A for 2)	3
Supporting oneself	d870	5 (24)	2
Community events	d910	9 (43)	2
Recreation/leisure	d920	10 (48)	3
Practising religion	d930	9 (43)	2
Input into community decisions	d950	12 (57)	1

**Table 3. Factors affecting participation**

Factor	ICF code	Number of participants reporting difficulty (%)	Number reporting large or total difficulty
Beneficial objects available	e115, e120, e125	13 (62)	2
Physical layout of land	e210	16 (76)	9
Weather	e225	14 (67)	6
Light conditions	e240	3 (14)	1
Sound quality	e250	2 (10)	0
Air quality	e260	6	2

More than half the participants experienced difficulties in transportation, meal preparation, and having a say in community decisions. Activities that many had difficulty participating in, included recreational or leisure activities, community events, and religious activities. Finding a job and work training was reported as a challenge by most participants who were not yet retired. Lack of funds seemed to be a barrier in some instances, including the ability to repair or replace equipment that malfunctions, or to pay for dietary supplementation.

The majority of persons with disabilities reported receiving therapy and homecare assistance when required. Most were set up with the locally available transportation service. Many did not seek or receive regular review by physicians at the hospital. Some did not seek help even

with sudden changes in health leading to additional medical impairments. They cited the reason for not seeking help as being a lack of action when they had previously sought assistance. Many voiced concerns that were not previously identified or documented in their hospital charts, as shown in Table 4, which also documents the numbers of actions taken 3 months after the initial registry was provided to WGH shortly after the on-site visit. Areas of participant-identified concern that had not been documented in hospital records in 32 instances, included aspects of bowel and bladder care; equipment and assessment requirements as pertained to hearing, sight, or teeth; education regarding diet; psychological assessment and management; and the need for diagnosis and management of peripheral nerve, circulatory, sleep, and musculoskeletal symptoms. Other areas of concern included assessment of the need for orthotics, pressure stockings, vestibular retraining, and family counseling. Some cited not having a family physician, in a community served primarily by short-term physicians, as a reason for not having these concerns dealt with.

**Table 4. Documentation and addressing of health or rehabilitation concerns identified by participants**

<b>Issue</b>	<b>Number of issues</b>	<b>Health professional aware</b>	<b>Issue resolved 3 months later</b>
Awaiting assessment	19	3	3
Awaiting management	8	4	-
Awaiting equipment	25	12	4
Awaiting home modifications	9	3	-
Action required by participant/family	3	2	-
Action required by Community	15	-	-
Requiring education/counseling	10	2	2

Some concerns related to a lack of local services. These included swallowing, speech and language assessments, identification of resources and funds for disability-related expenses, and management of psychological health. Uncertainties of rebooking cancelled procedures that were to occur outside of the community may linger indefinitely as participants remain uncertain as to whom to contact. Staff reported a concern with respect to discharge of

persons who received care in other communities, and returned with inadequate supports or communication with local health care providers. They also reported insufficient personnel positions, coupled with difficulty in recruiting personnel as a challenge.

Many waited a long time before receiving equipment, probably related to two levels of funding that many have to navigate: the Assistive Devices Programme (10), and the Non-insured Health Insurance Benefits programme (NIHB, 11), which entailed more paperwork and longer waits for approval than for non-aboriginal persons. There was a range in the waiting period for equipment, depending on channels through which they were approved and obtained. For example, most people received raised toilet seats and grab bars almost immediately, whereas wheelchairs and certain types of walkers took much longer, up to 2 years, though there was no consistency reported in the duration of wait. Provision of orthotics has improved recently, since an orthotist has been coming from out-of-town. Also, participants who might benefit from power mobility equipment tended not to have them prescribed, possibly related to funding, access, and storage challenges.

Home modifications generally took longer to complete, from 3 months to 4 years, as reported amongst those who have had them completed. Many others continue to await renovations. The majority of participants rent their homes from one of the two bands with land in Moose Factory, and the housing department is reportedly responsible for renovations. Some participants reported having incurred additional expenditures due to inadequate original construction of ramps.

Terrain, weather, and high cost of food and other essential items were all mentioned as barriers to community participation. Roads are unpaved, dusty when dry, and muddy when wet, despite improvements that have been made in drainage and grading. Being an island, residents of Moose Factory travel off the island by boat for three of four seasons, or by land vehicles in the winter.

Participants were asked for suggestions to improve their participation and quality of life in their community. Some reported motivation as an issue, given the difficulty in actually getting out to do things. Many suggestions were made, from installing higher seats in public places such as the airport and hospital waiting room and cafeteria, to installing an elevator at the WGH, to allowing persons with disability to use the more stable and accessible barge rather

than small motor-boats. Upon further inquiry, prior to a year ago, persons with disability were allowed to use the barge, but current concerns about safety of the barge led to a change in policy.

Table 5 lists some of the more common suggestions, along with the numbers of participants who expressed them. The most common suggestion was to pave the roads in the community, as they offer poor access for persons with mobility or visual impairment, but also cause many respiratory difficulties, particularly on dry, dusty days. Improved access of the main entrance to the community arena was also mentioned. Most houses are not accessible to wheeled mobility equipment, and since many would like to maintain their many social connections, a more accessible general building code may be beneficial. There is a transportation service for elders and persons with disabilities, but ability to transport wheelchairs is limited. Extended hours were suggested, to support participation in social activities on weekends and evenings. There is a reluctance by persons with disabilities to rely on their families for transportation to social events that family members are not involved with, leading to social isolation. Though there are apartments for elders, more are required, and accessibility needs to be improved to support independence. For example, cupboards and counters would need lowering for wheelchair users. Apparently, a nursing facility had been considered in the past, but because of regional limitations, the closest nursing facility remains in a different community quite a distance away. Persons with disabilities wishing to be gainfully employed reported difficulty finding work opportunities. Most persons with disabilities felt respected by others, but a need for general education of the community with respect to the challenges they face, and disability awareness was also identified.

**Table 5. Common suggestions in order of frequency reported**

<b>Suggestion for community leaders</b>	<b>Number of participants reporting suggestion</b>
Improve roads/install sidewalks	15
Improve boat access	5
Install a ramp at the arena	5
Plan inclusive community activities	5

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Provide accessible housing	4
Build a nursing home	4
Educate the public about disability	4
Provide home renovations ASAP	4
Enforce a general accessible building code	3
Provide wheelchair accessible transportation	3
Extend the schedule for accessible transportation	3
Provide raised seats in public places	2
Extend boat operation schedule	2

## **DISCUSSION**

Optimising participation of persons with disabilities is one of the ultimate aims of rehabilitation. This effort to identify the needs of persons with disabilities uncovered several opportunities for improving their participation in this northern Canadian community, largely comprised of First Nations persons. Potentially beneficial changes include improved communication at the individual and community levels, as well as with health providers in distant communities. Larger, systemic considerations of health care provision need to be undertaken. Participants also provided suggestions for community leaders to consider in order to improve community participation, and potentially quality of life, for persons with disabilities and those who care for them in this community, where the family unit appears to be generally strong and healthy.

At the individual level, the registry is an attempt to ensure continuity and completeness of care. The WGH has demonstrated in the three months since receiving it that the registry can be used to document when interventions are completed, and which areas need ongoing involvement. The research director at WGH and the medical records department have assumed responsibility for transforming it into a living document, in other words, an electronic record, with the intent that it be accessible by physicians and personnel in the Physical Therapy Department. In the coming months, management of the registry will lie in the hands of those with access to it. Information can be updated and the registry can be populated with new participants. Statistics may be summarised from time to time, to monitor progress. Perhaps, in time, community health providers might be able to access the registry, since many issues remained undocumented by hospital staff, whereas community health providers

may learn about issues sooner, as they visit patients in their homes. Closer communication between community and hospital providers may reduce the numbers of unresolved issues that are not identified or addressed. Also, closer communication between the housing department that completes home renovations, and the Physical Therapy Department may be beneficial in ensuring that home renovations are the most appropriate for the individuals they are meant to benefit. The services of a social worker would be helpful in dealing with funding issues, and for counseling.

Overall coordination of health care needs to consider ongoing contact with persons with disabilities to ensure completeness, as many seemed to remain silent in voicing their needs, questions, and unresolved issues, unless specifically asked. Some persons with disabilities remain in their homes, relying primarily on family support, and may not be aware of services that may be available or beneficial to their ability to participate in the community. Many are reluctant to ask for help, or use services that seem already stretched, and have demonstrated resourcefulness and relative self-sufficiency. Those awaiting home modifications or equipment often seemed to have no idea as to when these would be provided. More regular communication between various providers may help to answer such questions. Health service planners may wish to consider increasing rehabilitation management in the region. In other areas of Ontario, the Community Care Access Centre (CCAC, 12) provides case managers, and a host of services that are available through this programme, including speech language pathology, dietitian, and social work services. These do not seem to be available in Moose Factory. CCAC services are available in communities such as Timmins, and to a lesser degree in nearby Moosonee. Increased psychiatry involvement might be considered in the Moose Factory area, to provide completeness in rehabilitation management.

Coordinated discharge processes from distant acute hospitals may better support health care provision for the local population. A suggestion by hospital staff included instituting a policy that all hospitalised patients from the catchment areas of the WHA should be transferred to the WGH before being discharged into the community, so that appropriate supports and equipment might be arranged prior to patients returning home. For such a policy to be effectively instituted, all those impacted would need to be informed by appropriate senior management personnel in the WHA: these would include all distant hospital discharge planners, air ambulance and transportation personnel, community health providers, and community

members. Explorations between the WGH and partner hospitals of each hospital's capabilities and limitations may ease understanding and clarify expectations.

A Health Canada website (13) discusses the interesting phenomenon of reduced Ontario Health Insurance Plan (OHIP) use by First Nations communities, and resultant cost transfers to the federal NIHB programme. Services available to First Nations communities should include what is available through OHIP, in addition to what is available through NIHB, and one would expect better coverage than the average population, not worse, for First Nations persons, if availability and utilisation were maximised. Because of the challenges of dealing with multiple levels of funding, and inherent delays or inadequacies in service provision, some are proposing an integrated health funding programme (13), the argument being that if control of funding is put into the hands of the local communities, then perhaps they may be better able to institute services as they need them, and not be unduly affected by other considerations such as structure of Local Health Integrated Networks. They might be able to access the specialists and services they require. As an example, persons with disabilities in Moose Factory, which is within the North East Local Health Integration Network (LHIN, 14) should usually turn to Timmins for specialist care, based on the catchment area of the LHIN. However, there are no psychiatrists based there. Therefore, at the present time, psychiatric care is provided through Kingston, when requested, through the Queen's Weeneebayko Programme (15), with joint provincial and federal funding, and the Ontario Telemedicine Network (16), funded by the government of Ontario. Health service delivery is a complex phenomenon, and much thought and planning would need to be invested for successful transitions.

The cohort of persons with disabilities that was enrolled in this first version of the registry demonstrated some characteristics that community leaders and programme planners may wish to note. The majority had some type of musculoskeletal impairment, with implications of pain and disability. Limited vision was another area of concern for the more elderly participants. Diabetes was present in about half of the participants, and directly contributed to impairments; relatively younger persons seemed to be affected by diabetes, in keeping with other available data, which suggests that incidence of Type 2 diabetes is higher in the aboriginal population, and occurs in children as well (17). Participant numbers was somewhat limited by time available on-site, though the Physical Therapy department indicated that

there were no other persons with disabilities that they were aware of. This study did not include needs of children with disabilities in the community, and a future study of children's needs may be helpful to inform community leaders.

Overall, participants were well satisfied with the level of community support services available to them. Their level of participation could be improved, however, when compared with that of persons with disabilities in other Canadian communities (18). Participants provided inputs as to what community changes may positively influence their ability to participate in the community. Many suggestions related to accessibility, including accessible roadways and sidewalks; accessible land and water transportation services with availability during evenings and weekends; accessible public buildings with appropriately constructed ramps at front entrances and accommodations such as raised seats, in public places such as the local arena; and accessible housing. A meal delivery programme may help people remain in their homes longer, since the majority of participants identified meal preparation as a concern. They often relied on families to provide meals, but some had no such support systems. Supported living, such as a care facility, would help support persons with disabilities in their own community, rather than in distant communities such as Cochrane, where the nearest nursing facility exists. The only other option currently being employed is for persons with disabilities who require care giving to stay indefinitely in hospital. Increased community awareness may allow event organisers to host inclusive activities for persons with disabilities to participate in. In addition, for younger persons with disabilities who would like opportunities to find gainful employment, incentives and a general expectation of employers to provide accommodations, could be developed.

It is hoped that the registry will, in the hands of the WHA, become an active record that can be examined from time to time for data pertaining to persons with disabilities in Moose Factory. More information would be obtained as and when data for more persons with disabilities are added to the registry. Such information could be combined with information from other endeavours, such as the Regional Elder's Programme (7). The data suggest that actions at multiple levels have the capability of positively influencing the lives of persons with disability.

## **CONCLUSION**

Understanding of issues by community leaders is important for persons with disabilities (19). This report shares information about persons with disabilities that community leaders may find useful in community planning. It provides leaders with an awareness of causes of disability in the community, and potentially modifiable factors that impact the lives of persons with disabilities. Leaders may wish to facilitate involvement in persons with disabilities in identifying community needs and decision-making at the community level, encouraging self-advocacy, in order to address environmental and social barriers.

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