



*Canadian
Paraplegic
Association
(N.B.) Inc.*

*Association
canadienne des
paraplégiques
(N.-B.) Inc.*

Client Needs Assessment Final Report

September 2008

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Accessibility

“When I go to restaurants, is there going to be a booth I can park myself at? Am I going to be a bother to others?”

“Building code requirements – better standards should be made.”

“The accessibility around town, even the older people and able bodied people are tripping over the sidewalks. There needs to be a big improvement so everyone can enjoy getting out.”

“I’d like to see more restaurants be accessible, they need more than just ramps. Older buildings are being used as an excuse; people with disabilities deserve to eat where ever they want to.”

“Even places that are supposed to be accessible are not. There are lots of issues with buildings and washrooms, there are minor problems with a lot of washrooms, sidewalks, and there are a lot of places you just can’t get into.”

Availability of information

“We need to be provided with more information about what is out there.”

“There is a serious lack of communication.”

“I’d like to be made more aware of resources where help is available and accessible.”

Attitudes

“People need be better educated about disabilities.”

“People’s attitudes are improving but still need a great deal of work.”

Financial Assistance

"There needs to be some realism in terms of our expenses."

"I need a ramp on my house but I only get assistance checks so often."

"Money is a problem, being on a fixed income, it isn't much help."

"We should be allowed to make more money than we can right now."

Home support

"I am afraid of the future. If my wife gets sick and is not able to care for me I am fearful of what that may mean. I would need outside support, but can I afford it? I am fearful of being put in a nursing home."

"I can't find a home support worker who will work on a Sunday. I still need them on weekends."

Housing

"I was in a two year program at [an independent living centre] but ended up being there for 8 years because there was nowhere for me to go afterwards."

"I've been searching for a year and a half for something [housing] suitable. There should be more available. Maybe there is a lot out there, but I'm not aware of it."

"The rules about housing and subsidizing, they make it impossible for someone who is disabled to get a reasonable place around here. It wasn't already wheelchair accessible so they said it needed \$8000 worth of work and would take two months to do it. If things are going to take that long we'll never be able to move out...because the government took too long to get back to me about subsidizing and renovations, I couldn't take it."

Recreation & leisure

"I don't do a lot since my accident. I don't know what is out there for people in wheelchairs."

"It's nice to get out, instead of just sitting around all the time."

"Living in a rural area there is nothing. If you don't own your own car you can't go anywhere. People just stay in their house; there is no way to get anywhere."

"I don't do much; there isn't a lot to do in rural areas. If there was more stuff around it would be important, but there is nothing available."

"I don't do much. I'm kind of a loner."

"Being active keeps the mind from wandering."

"Not a lot of modified fitness programs available, or at least that are advertised."

"I'd like to be able to do things at night, but it seems like nothing is available."

"We need to have a reason to get up in the morning."

Transportation

"...because if I'm staying in the house watching TV and there are places that I could go and people tell me they have this or that, to get there, if I don't have a vehicle, what do I do? How can I get there?"

"If I didn't have my own vehicle I'd be stuck inside all the time."

"Transportation is a large problem."

"It would be nice to have a taxi company that is accessible. I could go to a Saturday night movie."

Summary

The objective of this project was to gather specific information about the unmet needs of people with spinal cord injuries (SCIs) and other mobility-related conditions in New Brunswick (NB). The needs assessment was designed to identify the major service gaps and barriers throughout the province in order to help improve programs, services and public policies that address the needs of persons with mobility-related conditions. The results of the tool are intended to be used as an information resource for agencies who serve this population and to ultimately assist with the development of goals for services and public policy today and in the future.

A mixed method design was used and included both quantitative and qualitative components. Multiple areas were addressed in the assessment, including: education and employment services; access to general and mental health services; equipment and financial support; housing and independent living centres; physical rehabilitation; and public and private transportation. Special attention was given to recreation and leisure programs as the importance of leisure education and participation is often overlooked.

Highlights

- 60% of participants were male; 43% of participants were between the ages of 40-55; and 47% indicated that they live in a rural area of NB.
- Challenges with accessibility were the most commonly recognized difficulty for respondents.
- People were the most dissatisfied with their current transportation, housing and financial support services.
- Physical rehabilitation and home support services were identified as the most satisfying services received.
- Recreation and leisure, peer support, and family support services were most frequently identified as desired but not available.
- Over half of the respondents indicated that they are content with the overall health services they receive from doctors, clinics and hospitals.
- Numerous negative feelings about discrimination, attitudinal barriers and the way people with disabilities are often treated by others were expressed.

Introduction

In 2006 it was reported by Statistics Canada (2006) that 17.2% of New Brunswickers are living with a disability and 11.6% of New Brunswickers have a disability related to mobility. Mobility-related conditions are the most common disability in New Brunswick (NB). There are many causes of mobility-related conditions including motor vehicle accidents, industrial accidents, sports injuries, birth disorders, and medical conditions, which may all result in permanent lifelong disabilities. It is without question that having some form of a disability can cause an increased number of day to day challenges. In order to support and better meet the needs of this particular population, action is required to provide adequate and additional services to help improve the overall quality of life of people with physical disabilities.

As a not-for-profit organization, the Canadian Paraplegic Association (N.B.) Inc. (CPA (N.B.) Inc.) is a leader in offering support, direct service, information and advocacy to New Brunswickers with spinal cord injuries (SCIs) and other mobility-related conditions. By reaching out and assessing their unmet needs, the following study can act as a first step to address gaps in services for this population.

Purpose

The purpose of this project was to gather specific information about the unmet needs of people with mobility-related conditions in the province. The needs assessment was designed to identify the major service gaps and barriers throughout NB in order to help improve programs, services and public policies that address the needs of persons with mobility-related conditions. While issues such as transportation, accessibility, finances and housing were of key importance, questions pertaining to recreation and leisure were also emphasized. Through the use of personal phone interviews the needs assessment results address the unmet priorities of persons with mobility-related conditions and may be used as a planning document to support funding, grants, programs, partnerships, and an overall improved quality of life for those who face extra challenges on a daily basis.

Data collection

The needs assessment tool was developed through the use of several previously administered needs assessment, questionnaire and survey models from similar provincial and national agencies. It included the collection of demographic information, and both quantitative and qualitative questions pertaining to potential service gaps and barriers. For a full copy of the Needs Assessment survey, see Appendix A (for a French version of the Needs Assessment survey, please contact the CPA (N.B.) Inc. office). A

bilingual recruitment flyer was mailed out to a CPA (N.B.) Inc. client list including current and former clients with SCIs and other mobility-related conditions (see Appendix B). The flyer explained the purpose of the assessment and requested that interested participants contact the CPA (N.B.) Inc. office to set up a phone interview appointment. A total of 30 personal phone interviews were completed and lasted between 15-60 minutes each, depending on the issues identified by the clients and their willingness to share their opinions and experiences. Upon completion of the interview period (July-August 2008) the data was compiled and analyzed. The following sections offer a context for the information that participants shared.

Limitations

A few limitations should be noted. Firstly, participation in the needs assessment was based on voluntary agreement by those who received the advertisement flyer in the mail. Assuming the flyer was received, it was then up to the recipient to decide whether to call and complete the survey over the telephone. Also, despite a bilingual recruitment flyer being mailed out, a large majority of respondents identified their preferred language to be English; however this one-sided percentage is not representative of the current CPA (N.B.) Inc. client base.

A final constraint to be noted is based on Section 2 of the needs assessment tool. The service options were limited to only specific answers, and did not allow for participants to expand on their experiences within those particular service areas (e.g., when asked if they had received poor, good or excellent service in regards to transportation the participants would provide their answer and continue to discuss all their experiences with that particular service). When told they would have that opportunity at the end and then re-cued when the time came, they were sometimes in a different frame of mind or had lost their train of thought. In the future, Section 2 may be most valuable as a checklist with space to insert comments made by the participants. Other options to improve the flow of the survey would be to provide the participants with a copy of the tool prior to their appointment, or conduct the interview in person for increased control and so the participants could see the actual document.

Data analysis/results

The survey was composed of five sections: Section 1 – *Demographic Information*, Section 2 – *Services Checklist*, Section 3 – *CPA (N.B.) Inc. Evaluation of Services*, Section 4 – *Recreation & Leisure* and Section 5 – *Major Barriers (overall)*. Sections 3, 4 and 5 were composed of more qualitative open-ended questions which provided a bit more flexibility and opportunity for the participants to expand on their opinions and experience. Please note that Section 3 – *CPA (N.B.) Inc. Evaluation of Services* is for

internal use only and will not be discussed in this report. However, it should be noted that results from this section were quite positive.

In both the quantitative sections (Demographics and Services Checklist), 30 (the number of surveys completed) was consistently used as the denominator in determining percentages. In some cases the survey allowed participants to provide more than one response or none at all. As a result, some questions may have a higher than 100 percent response rate and some may have a lower response rate. The qualitative sections (Recreation & Leisure and Major Barriers) were analysed through the use of data coding and identifying common and emerging themes based on the information provided.

Section 1 - Demographic information

Participants were asked to respond to the demographic questions based on their present situations at the time of their interview.

Gender

As seen in Table 1, 60% of respondents were male (n=18) and 40% were female (n=12).

Male	18	60%
Female	12	40%

Age

According to Statistics Canada (2006), people between the ages of 45-64 years have the highest disability rate in NB (38%). As seen in Table 2 this trend is reflective with the needs assessment data as the greatest number of survey respondents were between the ages of 40-54 years (n=13, 43%). The second highest response rate was between the ages of 55-69 years (n=10, 33%).

≤ 16	0	0%
17-24	0	0%
25-39	7	23%
40-54	13	43%
55-69	10	33%
≥ 70	0	0%

Language preference

As demonstrated in Table 3, all but one participant indicated their preferred language was English (97%, n=29).

English	29	97%
French	1	3%
Other	0	0%

Area of residence

Region 3 (Fredericton/Woodstock/Minto) had the highest number of participants (n=13, 43%), as demonstrated in Table 4. Region 1 (Westmorland, Albert & Kent Counties) had the second highest (n=7, 23%) and Region 2 (Sussex, St. Stephen, Saint John, Fundy Isles) was third highest (n=5, 17%).

R1 (Westmorland, Albert & Kent Counties)	7	23%
R2 (Sussex, St. Stephen, Saint John, Fundy Isles)	5	17%
R3 (Fredericton/Woodstock/Minto)	13	43%
R4 (Edmundston/Grand Falls)	0	0%
R5 (Campbellton)	1	3%
R6 (Bathurst & Acadian Peninsula)	2	7%
R7 (Miramichi)	2	7%

Type of location

Table 5 shows that 53% (n=16) of those who responded identified themselves as living in an urban location, while 47% (n=14) indicated they were living in a rural setting.

Urban	16	53%
Rural	14	47%

Living arrangement

When asked about housing and their current living arrangement, Table 6 shows that 47% (n=14) of participants indicated that they own their own home. Additionally 40% (n=12) of participants indicated that they rent an apartment or house and eight stated that the apartment was subsidized through NB Housing. Another 13% (n=4) of respondents stated that they live with family/friends. No other forms of living arrangements were identified.

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Living Arrangement	Count	Percentage
Own a home	14	47%
Rent an apartment/House	12	40%
Living with family/friends	4	13%
Subsidized housing	8	27%
Hospital/Medical Facility	0	0%
Long-term care/Nursing Home	0	0%
Transitional living facility	0	0%
Group Home	0	0%

Education

When asked about the highest level of schooling completed, Table 7 indicates that the completion of a college/university/technical school degree was the highest response at 33% (n=10). Also shown is that 27% (n=7) of respondents indicated they completed some college/university/technical school while high school is the highest level of education achieved for another 27% (n=7).

Education Level	Count	Percentage
Grade 1-6	0	0%
Grade 7-9	2	7%
Grade 10-11	2	7%
HS/GED	7	23%
Some College/University/Technical School	7	23%
College/University/Technical School	10	33%
Graduate School	1	3%
No Schooling	1	3%
Other training/education	0	0%

Source of income

Canada Pension Plan was the most frequent source of income for participants (40%, n=12). Table 8 also shows that 33% of respondents received Provincial Income Assistance (n=12) and 13% (n=4) were employed part-time. Only two (7%) of the participants were currently holding full-time employment.

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Source of Income	Number of Participants	Percentage
Disability Insurance	2	7%
Employment Insurance	0	0%
Employed Full-time	2	7%
Employed Part-time	4	13%
Canada Pension Plan	12	40%
Provincial Income Assistance	10	33%
Family Members	0	0%
Student Loan	0	0%
Band (Aboriginals)	0	0%
Other: Medical Leave	1	3%
Investments	1	3%
Workers Comp.	1	3%

Type of disability/condition

Table 9 indicates that SCI was the most common form of mobility-related condition among participants, with seven identifying paraplegia (23%) and seven identifying quadriplegia (tetraplegia) (23%). Four participants identified multiple sclerosis (13%), while three indicated muscular dystrophy (10%) and three were living with spina bifida (10%). A number of other disabilities were identified as shown in Table 9.

Disability/Diagnosis	Number of Participants	Percentage
SCI - Paraplegia	7	23%
SCI - Quadriplegia	7	23%
Multiple Sclerosis	4	13%
Muscular Dystrophy	3	10%
Cerebral Palsy	2	7%
Traumatic Brain Injury	2	7%
Spina Bifida	3	10%
Fibromyalgia	0	0%
ALS	0	0%
Other: Stroke	1	3%
Spinal Muscular atrophy	1	3%
Rheumatoid Arthritis	1	3%
Shingles	1	3%

Section 2 – Services checklist

The needs assessment identified 14 service areas and looked to determine which were of highest priority in reference to unmet needs. If the service was used by the client, their level of satisfaction was requested on a scale of *Poor*, *Good* or *Excellent*. There were also options if a service was needed, but the client had never received it or had no access to it, as well as if the service was not needed or did not apply to the participant. Participants were also reminded that they would have a chance to expand on their

rankings further along in the interview. The following is an outline of the highs and lows based on the feedback, while a complete numerical representation of the checklist results can be found in Appendix C.

Strengths

According to the checklist results, the highest level of satisfaction was in regards to equipment, with 50% (n=15) of participants indicating the services they have received in regards to acquiring, financing and replacing assistive or rehabilitation equipment have been *Excellent*. Home support and physical rehabilitation were also rated fairly high, both showing 43% (n=13) of respondents who rated their experiences as *Excellent*. Additionally, 57% of participants (n=17) indicated their experiences with overall health services, such as access to family doctors, health clinics, emergency services and hospitals was *Good*.

Services in need of improvement

Public transportation was rated very low with 57% (n=17) of participants marking it as *Poor*, while only 13% (n=4) of people gave it a score of *Excellent*. The second lowest service was housing with 40% (n=12) of people identifying their experiences with affordable and accessible housing to be *Poor*. Additionally, 33% (n=10) of participants feel the financial support they receive is also *Poor*.

Services that were identified as being needed, but not accessible were recreation/leisure (i.e., access to programs and services) at 40% (n=12), peer support (i.e., local disability support groups or individual peer mentoring) at 20% (n=6) and family support services (i.e., support, counselling and education for family members) at 17% (n=5). Other services such as education, employment, mental health services and independent living centres had high service not needed/not applicable response rates.

Section 3 – CPA (N.B.) Inc. evaluation of services

The CPA (N.B.) Inc. Evaluation of Services data was analyzed and is available in a separate report.

Section 4 – Recreation & leisure

The following section included six open ended questions specific to recreation and leisure including past and present participation levels. The questions also looked to identify what types of programs and services the participants would like to see available,

their view on recreation and the role it plays in their life, as well as the major barriers that may prevent them from taking part in activities in their communities.

Recreation and leisure participation

The first question asked the participants to identify what types of recreation or leisure activities they presently participate in, as well as what types of activities they did prior to their injury or onset of their condition. If participants had difficulty recalling their leisure pursuits they were cued with questions such as, "What do you do in your spare time? What types of activities did you participate in before your injury/condition? Are you still able to enjoy some of those same activities? What are some new things that you've started since your injury/condition?"

Previous recreation participation

The majority of survey respondents were able to name several activities they participated in previous to their injury or onset of their condition. Things such as karaoke, singing, playing instruments and dancing; community concerts, outings, going to restaurants and visiting friends; sports such as football, baseball, rugby, fitness, golf, mini-golf, and curling; camping and being outside; and cleaning and helping around the house were just some of the activities that were mentioned. It should be noted that many of the pre-injury/condition recreation and leisure pursuits would be considered active doings, while not a single participant identified sedentary activities such as watching TV, reading a book or using a computer.

Present recreation participation at home

The next question asked the participants to identify the types of activities that they currently do around their homes. In contrast to many of the activities done prior to their injury/condition, the top five responses can be labelled as inactive pursuits. Using a computer was the most frequent response (n=20) followed by watching TV (n=18), watching movies (n=15), reading (n=15) and playing games/cards (n=7). Activities such as listening to music (n=5), followed by talking on the phone (n=4) were also mentioned repeatedly. Other activities include spending time with pets (n=3) and socializing with neighbours (n=3).

As far as current active leisure pursuits around the home, the responses were few and far between. Only six participants identified doing things around the yard (e.g., gardening) (n=6) and only three participants indicated that they do daily exercises (e.g., stretching, stationary bike) (n=3) when at home. A mere two participants mentioned going for a wheel/walk as a leisure activity when around the house.

Painting, collecting, working with the hands (e.g., architecture design, drafting, carpentry), cooking and spending time with family were each mentioned by at least two participants. Other activities such as drawing, writing, video games, snowmobiling, restoring antique cars, radio bingo, watching horses, relaxing, studying, bible study, and meditation were also shared.

Present recreation participation outside the home

Next, the participants were asked about participation levels in regards to activities done outside of the home. This question yielded a bit of hesitation but did show a bit more variety and an increased number of active leisure pursuits. However, it should be noted that some clients (n=5) indicated that they do not participate in any form of recreation or leisure outside of the home due to an assortment of reasons such as lack of interest or lack of availability. The most frequently mentioned activities done outside of the home were going to the movies (n=9), visiting friends/family (n=9), shopping (n=8) and attending community events such as concerts, parades, fireworks, etc. (n=6).

Participants identified bowling (n=4), pool/darts (n=4), walking/hiking trails (n=3), going to the park (n=3), exercise classes (modified yoga, massage, physiotherapy) (n=3) and swimming (n=2) as some of the more active leisure activities they pursue. Going to bars (n=4), concerts (n=4), participating on a committee/board/council (n=4), going to restaurants, and going out to play games/cards (n=3) were other frequently mentioned recreational experiences of the participants. Doing volunteer work (n=2) and attending church (n=2) were each mentioned twice as well. Other activities participated in outside of the home are fundraising events, service clubs, playing basketball, going to the market, watching sporting events, visiting the library and acting as a peer counsellor.

Although it appears there are a lot of activities listed, on average each participant was only able to identify four activities done at home and two activities outside of the home. When asked about recreation and leisure involvement, a significant amount of cueing was given in regards to examples of possible leisure participation, as well as instructions that both structured and non-structured activities applied. The significance of activity response rates will be evident based on the data from the type of programs and services the participants would like to see available and the role that recreation and leisure plays in their lives.

Interest in programs/services

When participants were asked what type of recreation or leisure activities they would like to see available in their community there was a mix of both enthusiastic ideas and silence. The most frequent requests were in regards to physical fitness (e.g., accessible gyms, modified exercise classes and workout areas) (n=5), while being provided with more information about what is available for people with mobility-related conditions was

recommended (n=5). Four participants showed interest in wheelchair sport leagues, including leagues for power chairs (n=4); another suggestion by three different participants was accessible swimming programs, with assistance provided in the change rooms and getting in and out of the pool (n=3); and three others identified a meeting place to hangout, play games, talk with peers and watch movies as an ideal way to get out of the house, interact with others and share resources (n=3).

Other activities mentioned more than once were organized group activities with transportation included (e.g., accessible van pick participants up and transports them to activity), programs that are specifically for adults and/or organized by gender, and accessible mini-golf and curling facilities. Two people also proposed the idea of going into schools to help educate young people about injuries, diseases and disabilities. Other desired activities included accessible golf cart rentals at public golf courses, bowling and pool leagues for people with disabilities, accessible bars and social clubs, modified yoga/Pilates classes, and an increase in night time activities and outdoor pursuits such as accessible camping facilities.

Also worthy of mention are the four participants who expressed no interest in new recreation and leisure services being made available. Responses varied from being content with their current leisure status while others had more negative thoughts of their capabilities and the potential for any accessible programs to be developed in their communities. A positive showing of the results is that based on the importance of society's emphasis on physical health and well being, particularly for those with disabilities, over half of the suggestions that were made are classified as being active recreation ideas opposed to more sedentary types of activities, thus showing that there is an interest in more physically demanding leisure programs becoming available.

Role of recreation and leisure

After thinking about which activities they presently do and those they would like to do, the participants were asked about the significance of recreation and leisure and what type of role it plays in their life. Vast arrays of reactions were noted. However the majority were along the lines to be expected. Over half of the participants emphasized the socialization aspect of recreation, as well as using it to help cope with and forget about their disability was also common. As exemplified in the following quotations, the simplicity of getting out of the house was also mentioned repeatedly,

"It's therapy, to get out of the house – big time therapy when you're in the state I am. You get cooped up and feel sick that you're in the house all the time. You don't have to think about anything else except having fun...out and having fun with friends, you don't think about problems."

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Another participant said,

"It's great. You're doing something, you get out of the hole, you feel better when you can do stuff instead of staying home doing things alone. If not, after awhile its hard if you get stuck in a rut...I want to show people who can walk that people in chairs can participate too, teach them how to react, I want to do things together."

A third person adds,

"For me, getting out helps maintain my sanity; if I stay in the four walls too long I get cabin fever."

As demonstrated in the following remarks, a common benefit identified by numerous clients was the influence recreation and leisure has on a person's mental and physical well-being,

"Anything you can do besides sitting in your chair and thinking about it can help you mentally. The more programs they have the better off we'll be."

Also quoted was,

"Getting out is good for your health, whether disabled or not."

Other noteworthy reactions to the question were that recreation keeps a person stimulated, feeling productive and provides an opportunity to do things for oneself; it keeps the mind from wandering, helps to maintain sanity, cope with depression and acts as a stress reliever; it provides independence, friendship, sportsmanship and the opportunity to be part of a community/group; it also provides a sense of belonging and meaningfulness; and as one gentleman said,

"Recreation? It keeps me alive. I'd be dead without it".

Participants were then asked how they feel when they are not able to participate in recreational activities. A wide mixture of vocabulary was used to describe the emotions they experience. The most common sentiments were feeling down, upset, depressed, excluded, hostile, frustrated, angry, discriminated against, lonely and having a "screw you" type attitude.

As evident by the current versus desired leisure participation, there is a strong interest for more group activities for people with mobility-related conditions, particularly offered in the evening. A keen interest was demonstrated for sport and movement type pursuits and local hang outs or clubs to congregate and socialize. When asked how they feel when they can participate in activities, positive emotions came alive and made their voices light up; when asked how they feel when they are unable to participate, feelings of hostility and depression were evident.

Major barriers of accessing recreation and leisure programs

Once the activities that people wished to participate in were identified and the role of leisure in their lives was explained, the next step was to determine what is preventing them from participating in the activities they desired, and why the number of things they do in the community is significantly fewer than the sedentary activities done in their homes. Transportation (n=20), which is parallel to findings in the *Services Checklist*, and accessibility (n=20) were identified as the most common barriers preventing them from taking part in recreation and leisure activities. When discussing the topic of transportation, the lack of late night services was repeatedly mentioned by numerous participants. One woman stated,

"I'm only 37 years old and I'd like to go to clubs or bars but can't because there is no way for me to get home late at night".

Another client made note about late night transportation and home support/attendant care,

"I need someone to put me to bed at night so I can't be out late. I can't go to a late show movie, concerts or bars because there are no late night attendant care services or transportation available at those times."

Another gentleman added that when booking transportation in advance, recreational outings have been bumped by more important outings such as medical appointments. Accessibility was also a heavily discussed issue, both in regards to recreation and in an overall general sense. One person indicated they always have to send a family member or friend to the facility ahead of time to make sure they will be able to access it. As one woman put it,

"I used to enjoy going out with my friends but can't anymore. For something like a retirement party I can't get into the buildings where the parties are hosted. I'm not a negative person, but kind of have to be sometimes because you don't want to get your hopes up and then be disappointed that you can't participate. Why build yourself up and then find out can't go. You get all ready to go out and then you show up to a six inch step."

Another woman talked about going out for a coffee with a friend,

"Just going out for coffee, the store put in (automatic) door openers, but there is still a five inch step!"

A third participant noted that,

"Some places you go will have (accessible) parking spaces but then no ramps. Sure you can park there but how are you supposed to get inside?"

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The high cost of leisure is another burden on people with a small fixed income. When asked about activities done around the home, one man said he liked to play on the internet and watch TV, however even those activities would be taken away from him soon because he was no longer able to afford the bill for his phone, internet and cable. Others mentioned the high costs of movie theatre tickets as well as high priced gym memberships.

Frequent discussion occurred about not knowing what types of modified programs are available or which existing regular programs are able to accommodate those with mobility-related conditions. Additionally, many participants discussed their anxieties of what other people think of them when they go out. One young man stated,

"I don't have any friends in wheelchairs and I don't see many chairs around. I figure they are all hiding and don't realize there are others out there because we all just stay indoors."

Another person said something holding them back from participating was the ignorance of others,

"The pressure of being out, people in a (wheel) chair can be shy. The ignorance of people staring and stuff, it can't be helped."

And one other man said the reason he didn't participate was,

"...the fear of not being able to keep up with others."

Other major barriers of recreational participation included living in rural areas, lack of programs in general, the cost of late night private transportation, a lack of accessible taxis, the cost of adaptations and equipment (e.g., sport specific wheelchairs), and a lack of companionship.

Evidently there are many reasons holding people back from taking part in recreational activities and many of the barriers mentioned were repeated over and over in different words amongst different emotions. Looking at the reactions to questions about leisure's role and how it affects them when they cannot participate, a clear picture emerges of the importance of eliminating barriers and providing programs for people with mobility-related conditions – programs as adequate as those for people without disabilities. In order to help this population improve their quality of life, it is areas such as recreation and leisure which create a sense of belonging and friendship that will improve both their mental and physical well being.

Section 5 – Major barriers

The final section of the needs assessment asked the participants to identify two or three of the most significant service barriers they face and provide suggestions for improvement. The most common response was accessibility, followed by transportation, housing and then financial support. The following is a reflection of each issue:

Accessibility

Many businesses have been enhancing the accessibility of their facilities; however the respondents still commented about poor accessibility standards as the number one problem they face in their communities. One client made the point,

“I pay taxes; I should have access to everything just like others.”

It was often recommended that building code standards be raised and ultimatums be placed on businesses to make improvements by a certain date or they will be shut down. As one man put it,

“Too many people are using old buildings as an excuse.”

Items such as ramps being too steep, automatic door openers not working or not existing at all, sidewalk conditions, large bumps and stairs, having to use alternate entrances to access services and a lack of accessible washrooms in public places were all mentioned repeatedly. Another man made a point about accessible parking spaces,

“They need to be wider than regular spaces. Many places have a designated spot but it’s so narrow that you can’t fit. They are geared towards seniors not for people in chairs, with space for a lift. It’s tight to get in and out, you don’t want to scratch other cars but they are so narrow that it’s tough for chair users to actually use them.”

Several people also mentioned that improvements to accessibility standards would help with independence in the community,

“More people could go out on their own without support workers if accessibility was better.”

And another stated,

“People assume they know what it means, but they have no idea. I didn’t know 20 years ago either (before having MS). Accessibility means that a person like me needs to be able to get around without assistance. People just assume that we’ll have an attendant, but it isn’t true.”

Transportation

As expected, transportation proved to be a popular response when identifying major barriers. Three items were common among the transportation complaints: the hours that transportation services are offered, the availability of buses and the lack of services to rural areas. Similar to the recreation section, many participants were dissatisfied with the hours that accessible bus services are offered. One person commented that,

“If regular buses run late at night then the accessible ones should too.”

Others suggested that more buses be made available and some discussed concerns as to how far in advance the bookings need to be,

“It needs to be booked weeks or almost a month in advance now, how are we supposed to know what might come up?”

Many people made comments about the lack of services to rural areas,

“I only live two miles outside of the city, but I can’t get the accessible bus.”

And another man talked about using his own vehicle from rural areas,

“There is no transit system in my area so I use my own vehicle, but with gas costs rising, soon I won’t be able to go anywhere on my fixed income.”

Not only was public transportation discussed as an issue but private transportation was also identified as a challenge. One client talked about his experience with trying to get funding for leather seats in his own van,

“We are buying a new van so we applied to get funding to have leather seats, so I can slide in (the second row) easier. We were denied; they said they don’t cover that type of thing. We don’t care about the leather; I just can’t get in the van with those other seats, I’m not able to move across them. If they could be leather I could slide right in and not need help.”

A few other suggestions included bringing in more accessible taxis for the night time and when the accessible buses are over booked. Also, adding more (kneeling) accessible buses to the regular transit system was proposed. One woman suggested that she would be fine with taking the regular transit service if she could actually get on it.

Housing

Affordable and accessible housing was commonly criticized by many participants and many suggestions were made for improvements. One woman stated,

"I can only afford to live in a mobile home but can hardly get from my bedroom to the kitchen in my wheelchair, it is way too small."

And others made reference to accessible design features that may relieve home support workers from some of their duties,

"I could do the dishes if my chair could roll up closer to the sink. I wouldn't need as much help and then they could spend time with others who need it more than I do."

Many people made suggestions for increased facilities,

"Complexes for people with disabilities would be ideal, like how they have them for the elderly."

And another added that they should be built with more than one bedroom for roommates or family members. Several people were of the same opinion that people with disabilities should be consulted prior to building new barrier free units. One woman mentioned she made a list of 40 items, such as lower light switches and wheel-in showers, which should be considered.

"The people who are in the chairs are the ones who know best; they should be asking us first."

A further suggestion was that people with disabilities be provided with more information about what is available to them and the amount of funding they can receive to make modifications to their own home. One participant claims he has not been in his own basement for 15 years because he can't afford to make modifications. And a final comment about housing,

"If they build it, we will come.... we don't want luxuries, we just want comfort."

Financial support

The fixed financial support that people receive was continually brought up, with particular reference to their inability to have any other sort of income without having to forfeit what they are receiving from the provincial government. People expressed an interest in having part-time jobs but fear that their funding will be cut off. One woman stated,

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"You lose benefits if you have too much income. They said that because I worked that year I didn't need the money anymore. There is really no way to make much money at all."

And another man's experience was,

"When I was working I was getting minimum wage and had to fax my pay stubs to my income assistance worker. Now, I thought the meaning of social services was just to aid a person while they got back on their feet. They take away any incentive that you get when you're working. My health card was at risk, I didn't have a pension, I had to be very careful. It's completely backwards to what it should be. As a person with a disability, I have a university degree and I can't use it because I get more money sitting on my butt at home than actually in a workplace doing something constructive!"

One gentleman described his struggles with supporting his family,

"\$120 a week, I can't support my three daughters on that and pay the bills."

Other fixed income related complaints were that they are not able to do anything because everything is so expensive, gas prices were too high to be able to go anywhere, and bills are coming in more often than assistance checks. Other mentioned that they had to pay for their own attendant care and dental work with limited income, and others mentioned the difficulties of living off of a disability pension. The high cost of equipment also proved to be a burden on some, as one woman described her need for a tilt chair. She has been unable to get funding for it because she was told it was a luxury, while she believes it is a must because of the number of pressure sores she endures.

Another man told his story,

"I was told I should have a new chair every five years. I had my first chair for six years and my current chair for eight. I need a new one, but can't afford it."

Discrimination

The way people with disabilities are treated was another commonly mentioned obstacle throughout the final section. The stigmatization, attitudes and even people staring can be hard to take. Many made reference to teaching people about disabilities,

"Educate people, they should be made aware of what people have to go through, instead of stares and snickers, educate people more, just getting into a stupid building, crossing a street, they take things for granted, it's ignorance of the public."

"Knowledge, people just don't know. Either they don't know or they don't understand."

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“People are very ignorant of what we go through, not their mannerisms, but their knowledge.”

Others made reference to being treated like a child and two people stated,

“Just because you are on wheels it doesn’t mean that you are mentally deficient. People on wheels have just as much up there as everyone else.”

And,

“It hurts when you look at us a different way. We’re all people; we just have different disabilities and abilities. We all think the same.”

Home support workers

When asked about the most significant barriers, many clients took the opportunity to advocate for their home support workers. They were clearly appreciative of the service and care they receive from these workers but demanded that they be paid more for their work,

“They keep raising minimum wage but my worker still gets paid the same. Soon it’s like she’ll be working for minimum wage, she deserves way more than that.”

And another noted,

“They should be better paid for hours and for gas, and receive benefits. It would cost less for the government to pay for my care workers than putting me in a special home and having to pay for that.”

Miscellaneous

There were several other items worthy of mention that people shared when discussing the most significant challenges they face. People emphasized the importance of being made aware of what is out there for people with disabilities, what types of services are available and what funding they may be eligible to receive. A few others suggested more Extra-Mural services, like physiotherapy, so they can receive their services from home. Others suggested more local support services throughout the province, including the rural and smaller communities; somewhere to go, a place to connect or a support network that is outside of the larger cities. Others commented on government processes:

"I went after the municipality a few times but they won't do anything until the provincial government does. Why do they have to wait? Why can't they just take the lead and make changes?"

And,

"There is so much red tape to getting stuff and it's a pain in the ass. You have to wait six months to a year for something you needed yesterday."

Evidently there are many glitches in the system causing unmet needs and barriers for people with disabilities. The reoccurring themes of accessibility, transportation and housing needs, as well as financial support and other miscellaneous concerns are an indication that these issues are of highest priority and need to be addressed and improved. A summary of the findings and recommendations follow.

Summary of findings

The needs assessment identified 14 service areas and aimed to determine which were of highest priority in reference to unmet needs among the participants. The service areas are as follows: education/training, employment, equipment, family support services, financial support, health services, mental health services, home support, housing, independent living centres, peer support, physical rehabilitation, recreation/leisure, and transportation. Accessibility is also included in the results as it was identified by the participants as the most significant barrier affecting the quality of life of people with mobility-related conditions. It should be noted that some services that people are dissatisfied with or claim they do not have access to may actually be available, however their inclusion in the results represents a problem within that service or a lack of knowledge about its existence by those who clearly need it. Below is a summary of the data for each of the 15 areas (listed alphabetically):

Accessibility

Many participants were critical regarding the accessibility of their communities; in fact it was the most frequent response when asked about major barriers affecting quality of life. Suggestions for enforced regulations and improved conditions were frequent.

Education/training

The majority of respondents indicated education or training for employment or upgrading skills did not apply to them; however for those who have received educational services their experiences were all positive.

Employment

Many of the survey participants did not have experience with employment services such as job preparation or placement; however, in some cases, this may be associated with the fear of forfeiting their social assistance income if they were to find additional financial resources via employment. Others may have complex health conditions which prevent them from working and others who were interviewed were seniors in or near retirement age.

Equipment

Experiences with obtaining and/or receiving funding for assistive devices such as wheelchairs, lifts, computers, and/or other aids and devices, was the most satisfactory category among participants.

Family supports

Many respondents indicated their family members have never received any type of education/counselling services to help care for their family member with a disability. A number of participants showed interest in this type of service becoming available, while others were unsure if their family members would choose to use this services or not.

Financial support

Based on the services checklist, there were mixed opinions on the amount of financial support received by the participants; however when given the opportunity to identify the most significant barriers, financial support was one of the most frequently dissatisfying services mentioned. Again, the inability to receive funding from other resources without losing their social assistance benefits was distressing.

Health services (overall)

Access to family doctors, health clinics, emergency services and hospitals were given an average score of "good" by the participants. No major praise or complaints were identified.

Health services (mental health)

Experiences with mental health services appeared limited or did not apply to the majority of the survey takers.

Home support

Many respondents were very pleased with the home support they receive; however a large effort was made by many to advocate for their workers to be paid more for the services they offer.

Housing

Accessible and affordable housing was by far a common problem among discussions. Many participants were very displeased with the amount of accessible housing available and proposed that more units be constructed with the consultation of the people who will actually be living in them.

Independent living centres

The few respondents who had experience with independent living accommodations were very pleased, while more facilities of this nature may fulfill the suggestions made by those who are dissatisfied with their present living situations.

Peer support

Local support groups or individual peer mentors would be beneficial to many of the participants, as very few of them have ever experienced such a service and showed interest in them becoming more available.

Physical rehabilitation

Many respondents were very pleased with the physical rehabilitation services they received, while others had never experienced this type of treatment.

Recreation/leisure

A severe lack of modified programs was identified and many suggestions were made, particularly in regards to more active leisure pursuits that can be done outside of the home with the right supports (e.g., transportation) and programs.

Transportation

The need for suitable transportation for people with disabilities remains acute, ranking very poorly, and suggestions for more buses, services to rural areas and late night hours were recurring.

Recommendations

The participants of the needs assessment shared their experiences and stories in hopes of influencing attitudes and promoting change. With the help of both their negative hardships yet their optimism for improvement, the following recommendations for further exploration and action were identified:

Accessibility

Eliminate the barriers caused by the structural environment. Place an increased emphasis on provincial and federal accessibility standards, encourage contractors to exceed minimum requirements, educate people on universal design and require total accessibility of all facilities (excluding personal residences).

Transportation

Extend and expand accessible transportation services. Public accessible transportation service hours should mirror those of the regular transit system as well as provide alternate arrangements during off-hours such as mandatory accessible taxi services. Financial assistance for modifications made to private vehicles should be available to all people with physical disabilities.

Affordable, accessible housing

Increase the number of affordable, accessible living units throughout the province. Require accessible accommodations in all communities based on a per capita population. Place a greater focus on designers and contractors to exceed minimum standards and provide tax incentives and/or grants to encourage new construction and modifications for accessible housing.

Employment

Explore additional incentives to ensure people with disabilities who plan to re-enter the workforce part-time or full-time will maintain access to essential benefits as needed (e.g., extended Health Card). This population should be encouraged to pursue employment if they desire, without fear of becoming financially unstable. Increasing their daily activity may also prove to alleviate some mental and physical health obstacles by them being productive and making a contribution to something in their community.

Recreation

Promote and provide active recreation for improved health and well-being. Recreation and leisure services need to be made more available to people with physical disabilities. A particular emphasis on active recreation is suggested to coincide with the increasing trend of health and wellness. Accessible public facilities and programs should be mandatory, while private businesses (e.g., fitness facilities) should be heavily educated and encouraged to be inclusive. Leisure education will help people find creative ways to be active and cope with their disabilities.

Education & awareness

Expand education and awareness initiatives. Disability awareness should stem from the federal, provincial and municipal levels into all communities throughout NB and should happen more than one week per year. People with disabilities may be a key partner in educating the public about disabilities and in the case of injuries, about injury prevention. The only way to remove stigma is to educate people.

Resource availability & awareness

Promote resource contacts and locations in all communities. Educating and increasing the awareness of service providers for people with disabilities is essential in order for this population to be aware of programs and services that offer support to people with disabilities. Organizations and agencies who offer these services need to increase their promotion and reach out to present and future clients with information and resources necessary (e.g., support groups, telephone counselling, funding programs). Making people with disabilities conscious of what is out there is another step forward in improving their overall quality of life.

References

Statistics Canada. (2006) *The 2006 Participation and Activity Limitation Survey: Disability in Canada*. Catalogue # 89-628-XIE – No. 3.

Appendices

Appendix A – Client Needs Assessment Tool

Appendix B – Recruitment Flyer

Appendix C – Services Checklist Results (Section 2)

Appendix A
Client needs assessment tool

Appendix B
Recruitment flyer

Appendix C
Services checklist results (Section 2)