

NeuroMatters

Connecting YOU to the Research

Community Participation After Acquired Brain Injury

The Ontario Neurotrauma Foundation (ONF) has long supported research on community participation for people with acquired brain injury (ABI).

ONF recognizes the key role that community participation can play in the lives of people living with ABI, but ONF is not a service provider. Rather, ONF works to create a positive impact on quality of life through developing relevant research to improve programs, services and systems for people with ABI.

To develop a comprehensive approach, ONF brought together experts to advise on community participation for people with ABI.

"Participation is an active concept, whether we are talking about people returning to roles they had prior to their injury, or about people finding new roles in the community that are meaningful to them," says Corinne Kagan,

Senior Program Director of ABI at ONF.

A brain injury can change a person's abilities which can make returning to pre-injury roles challenging. Sometimes, returning home from a hospital without appropriate supports can lead to social isolation.

"Brain injury is a life-long issue. It's very important that we get a grasp of the importance of long-term programs and which programs actually help people," said Kevin MacGregor, a person with ABI who advised ONF and contributes to various ONF initiatives on community participation.

The experts on ABI describe community participation as:

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- a philosophy, an attitude, an approach as well as an outcome
- providing a sense of self, giving one a sense of acceptance from "the group" on a level playing field
- an environment in which one can gently move beyond one's comfort zone with dignity
- participating in the ABI community with peers or in the larger community
- having age appropriate activities
- requiring community readiness and a welcoming environment

Together with its partners, ONF directs and supports research to inform and improve services for people with ABI, realizing that research has to apply to people's lives and the systems that support them.

The following three articles on the following pages detail some of ONF's ongoing work on community participation.



1

Banking on the Data**A short quiz**

What percentage of adults with a brain injury make regular use of a physiotherapist? How many adults with acquired brain injury (ABI) live independently? What percentage of children and youth living with a brain injury attend school regularly?

Know the answers

ONF knows that programs aimed at increasing community participation succeed when they address the needs identified by members of the community. But what services do people with ABI want?

For 20 years, the Ontario Brain Injury Association (OBIA) has collected data about children and adults living with brain injuries as well as about their caregivers, to better serve people with ABI. Until recently, the means of data collection was a questionnaire called CISL which stood for Caregiver Information and Support Link. Today's version of the questionnaire is called: "Ontario Brain Injury Survey". But the name isn't the only thing that has changed.

Recently, ONF partnered with OBIA to work toward their common goal of gathering more information about living with ABI and sharing this with stakeholders in a position to bring about change. OBIA and ONF put together an expert panel in October 2008 to review and help revise the original questionnaires which had been in use since 1989.

In addition to individuals with ABI, the panel included family members, service providers, insurance representatives, researchers, government representatives and OBIA staff.

Are the questionnaires worthwhile?

"We wanted to know: is this something that these people around the table see as being useful because if it's not then we're not going to take the next step of redesigning it," Ruth Wilcock, Assistant Executive Director of OBIA said. The consensus was a resounding "yes".

The survey results have been used by policy makers as well as by service providers and funding agencies. Researchers have made use of selected data from the database and their published works have helped to deepen the understanding of ABI in Ontario and beyond. The survey data has shown, for example, that the earlier the diagnosis, the better the recovery is for people with brain injuries. OBIA uses the survey to better plan service, advocacy and education needs, both for individuals and for the province.

Could they be improved?

Again, the consensus was "yes". The next step was to see how.

Two survey writers from the University of Toronto who were part of the panel, incorporated comments into new versions of the questionnaires. The new drafts were circulated and revised. "The goal was to come up with a questionnaire that was clear and concise," Wilcock said.

Over the summer of 2009, the new drafts were tested and revised again before a final version was launched at a meeting of the brain injury community associations in November of last year.

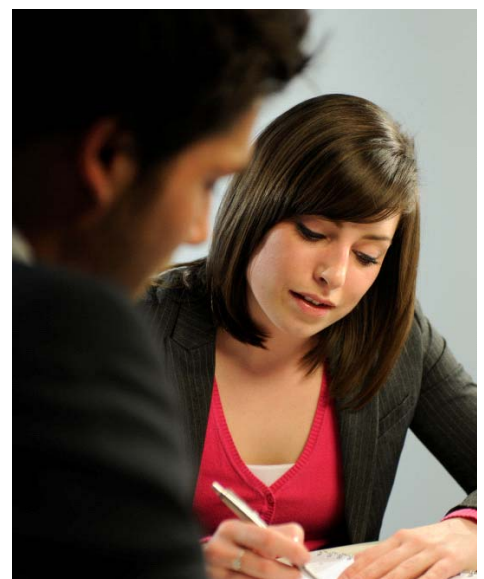
How the data will be used

Carla Thoms, Support Services staff member at OBIA, reported that 220 new surveys were completed as of early March. But this is only a start. OBIA wants to increase the

number of people completing the survey far beyond previous numbers. The greater the number of completed surveys, the better an idea OBIA and ONF have of the services, activities and needs of people with ABI and their caregivers. OBIA's next step is to promote participation in the survey beyond the brain injury community associations via hospitals and service providers. ONF is continuing to fund the development of the database so that survey results can be used not only for the annual reports but also for researchers interested in studying specific portions of the data.

OBIA is planning to make an online version of the survey available so that participants can choose the most convenient way to complete the survey (online or on paper).

The first report incorporating data from the new questionnaire is due next year and will be available to participants and interested stakeholders.



It's all up to you!

Are you interested
in taking the survey?
Go to: www.obia.ca

2

Making the Case for Best Practices

The puzzle

ONF was interested to find the very best evidence-based examples of community participation programs in the world. So, it funded best practices expert Dr. Richard Volpe of University of Toronto to find them and write them up in a collection that can be used as a resource for those interested in enhancing community participation for people with ABI. Volpe has produced best practices collections on a variety of topics including neurotrauma prevention.

The advisory committee

To assist Volpe, ONF put together an advisory committee of experts in ABI.

"The role of the ONF advisory committee is really important because we supply the expertise in brain injury in terms of where to find best practices and what kinds of things to look for, and what people need in a good program," said Kevin MacGregor, one of five members of the advisory

committee. "I am quite vocal about what features a program needs to have. A program needs to be dynamic, to be long-term so people can come and go to it, because brain injury is a long-term issue."

In addition to the ONF advisory committee, Volpe set up an international advisory committee and also works with an interdisciplinary group of top graduate students.

The selection process

The best examples of community participation programs are found and selected by means of a systematic and rigorous process.

Working from suggestions of the ONF advisory committee, Volpe's team scanned conference participation lists and journals for experts in the field who could lead them to further programs. They also found examples of best practices through accreditation bodies, journals as well as Internet literature and other searches.

International experts nominated programs and one nomination led to another and another, and soon Volpe had massive lists of candidate programs. "When we start to hear from a number of people that a program is particularly good, we investigate. Multiple referrals are a good sign," Volpe said.

Although the selection of programs is still ongoing, it looks as though some programs they are considering are from Ontario. "It just happened that we kept getting told to look at them, over and over," Volpe said.

"People running the programs we include have to want to share their ideas. That is one thing that we insist on."

The Casebook

"People running the programs we include have to want to share their ideas. That is one thing that we insist on," Volpe said. People whose projects are selected for the best practices collection become contacts for their programs. If someone wanted to try a program, the idea is that she could pick up the phone and ask "can you advise me on setting up



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a similar program?" The expectation is that the answer will be "yes".

"For this collection we are hoping to include approximately 20 cases with a mixture of best practices as well as promising practices in order to show the range of approaches to facilitate community participation," Volpe said.

ONF doesn't just want to know that a program works; it wants to know how and why a best

practice is successful. For each program, the team identifies what they call the "fidelity features". These are the essential, identifying features of the program. Some elements are essential to a program whereas other features are optional.

A particular program may be very good but not included in the collection for any number of reasons. Exclusion from the casebook does not mean that a program is not good.

Looking Ahead

The casebook is expected to be ready in the fall of this year and will include a directory of people involved in community participation projects worldwide. ONF hopes that some international best practices can be selected for demonstration projects in Ontario to look at whether they can be effective here. Similarly, if an identified best practice is in Ontario, ONF would want to look at what it can do to help others in the province have success as well.

3 Peers Are Doing It for Themselves

Who can best sympathize with how life changes after an acquired brain injury (ABI)? Who understands the challenges a person with ABI faces when returning home? Who really knows what day-to-day life is like for a parent of a child with a brain injury?

In our December 2007 issue, we presented an article about the Peer Mentoring Program run by the Ontario Brain Injury Association (OBIA) and supported with funding from the Ministry of Health and Long-Term Care. ONF is funding the Peer Mentoring Program's evaluation.

Background

OBIA's Peer Mentoring Program matches an ABI survivor looking for advice and support with a survivor who has gone through the same sorts of challenges. The program also matches family members (parents, spouses, adult children) and close friends with people in similar circumstances.

In peer mentoring programs two people enter into a relationship in which one person, the mentor, is more experienced than the other, the partner, who seeks advice or support. The OBIA program is run free of charge for participants.

In designing the program, Program Manager Michele Meehan drew on her experience designing one for the Canadian Paraplegic Association (CPA) Ontario. She also adapted the methods and training manuals originally developed by the Brain Injury Associations of New York and New Jersey.

To date, 15 of 20 brain injury community associations from across the province participate in the Peer Mentoring Program and well over 100 mentoring partnerships have been initiated. The majority of the partnerships last the maximum one-year term. In most cases, the mentor contacts the partner about once a week.

Since the program is conducted

"When it works,
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a great benefit"

by telephone and/or email, geography presents no barrier to participation. "The expansiveness of Ontario and the fact that such a program could reach under-served consumers in rural communities and in the north made it fantastic for Ontario," said Ruth Wilcock, Assistant Executive Director at OBIA.

Those interested in joining as partners are interviewed to find out what they are seeking in a mentor, how their injury is affecting them

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and how they hope to benefit from the program. The local Peer Support Coordinator then finds a match. Participants who join as peers receive training and sign confidentiality agreements.

Feedback and the ONF evaluation

Although the ONF-funded evaluation is currently still underway and the report is not due until 2011, early indications are promising.



“The feedback on the program has been really heartening,” Meehan said. “When it works, it’s of such a great benefit.” Partners report that the program reassures them that they are not alone.

Dr. Kathryn Boschen, the ONF-funded external Evaluation Director of the Peer Mentoring Program, adds that often there are unanticipated benefits for the mentors. She hopes to capture these in the evaluation.

The ONF evaluation is done with both mentors and partners by means of a questionnaire given before and after the partnership. For mentors, OBIA gives them a questionnaire on the day they receive training, and then at the completion of one year of being a mentor. For partners, a pre-match questionnaire is filled in once they have been interviewed and accepted, and a post-match questionnaire is done when their partnership comes to an end.

Based on a model used by the New York and New Jersey mentorship programs, the evaluation asks about participants’ health, moods, community participation, and the availability of support. The evaluation also



To get involved in the Peer Mentoring Program, visit: <http://www.obia.ca>

canvasses participants about their satisfaction with the program. Evaluations of the American programs concluded that mentorship improved participants’ knowledge of brain injury, improved their coping skills, and resulted in increased participation in their communities.

Boschen reports that data collection for the evaluation is proceeding well. “When analyzed, the data will allow us to make meaningful evidence-based comments about this significant Ontario-wide OBIA program. We will be examining the usefulness of the service to the injured person, their family members, and other significant people in their lives as they individually and collectively deal with the long-term challenges of brain injury in the community,” she said.

Data collection for the ONF evaluation will conclude at the end of this year and the results will be ready by next May.

Looking ahead

Meehan anticipates that the momentum established will continue to grow, attracting more participants.

4th National Spinal Cord Injury Conference

Niagara Falls, Ontario October 28 - 30, 2010

Consumer Outreach Program

The Toronto Rehabilitation Institute in collaboration with Ontario Neurotrauma Foundation will provide financial support to assist consumers living with a spinal cord injury to attend this conference. Consumers must agree to attend the full conference and provide

feedback to the conference organizers on the relevance and practicality of the presentations. Attendees are asked to share their learnings within their communities. The application is available at <http://www.torontorehab.com/education/scic10outreach.html>

Primary Healthcare Delivery

Where should we go from here?

Amidst advances in medicine and rehabilitation as well as shrinking government budgets and rising costs, the delivery of healthcare is shifting from hospitals to the community. Whenever possible, inpatient treatment must be replaced by what people are calling “primary healthcare” and “community management”. But what exactly is primary healthcare? And what is the best way to deliver primary healthcare for a person with a spinal cord injury?

Recognizing that primary healthcare is critical for people with SCI, the Ontario Neurotrauma Foundation (ONF) has funded several research programs on the topic over the past decade. Last year, ONF asked Sara Guilcher to summarize the findings of three research reports on primary healthcare for people with SCI. Guilcher, a doctoral candidate at the University of Toronto, was working on a policy practicum at ONF. The ONF-funded research reports summarized are:

1. *Needs Assessment Report: Developing a Comprehensive Research and Knowledge Mobilization Agenda on Primary Care for People with Spinal Cord Injuries in Ontario 2005*
2. *Centre for Effective Practice: Report to Ontario Neurotrauma Foundation 2009*
3. *“I am Able”: Population-Based Rehabilitation in a Family Health Team 2009.*

ONF was also interested in a review of recent government and academic literature on the subject and so asked Guilcher to integrate those findings with the report summaries.

What is primary healthcare?

Drawing on expert work in the field, primary healthcare is defined as:

1. medical services provided at the first point of contact with the healthcare system
2. healthcare that is involved for

the long term with the individual

3. comprehensive healthcare including the coordination of the individual’s care with other parts of the healthcare system.

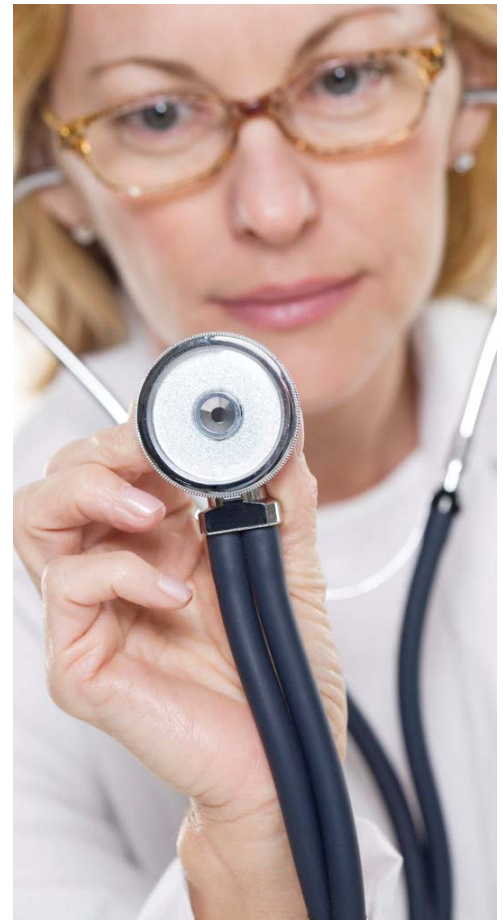
Problems with the most common model

The most common model of primary healthcare provision is the clinical approach in which services are provided to people with SCI via a community health centre or a family health team. However, this model has come under some criticism in addressing the needs of individuals with SCI. Critics point to long waiting lists, a lack of efficient care coordination and the resulting delays in treatment and appropriate case management.

According to the research, in the year following discharge from acute care, individuals in Ontario with traumatic SCI visit their family doctors three times more often than the general population does. Additionally one third of people with SCI find themselves readmitted to acute care within 12 months of discharge.

The knowledge gap, barriers and additional challenges

People with SCI have greater healthcare needs than the average person in Ontario, yet family doctors tend not to have the required expertise resulting in a knowledge gap. Many family doctors cannot justify the time and expense to become better educated about SCI especially if



their practice has only two or three clients with spinal cord injuries.

“The knowledge gap reported by family doctors and nurse practitioners points to the need for more specialized professional care,” Guilcher said. “But that raises a whole new set of problems regarding access and availability of specialists and the wait times to see a specialist are very long.”

In addition, there are numerous barriers to gaining access to primary care including lack of adequate transportation and finances, distance from facilities and attitudinal barriers.

A lack of preventative healthcare and too little communication among provider groups further undermine the success of primary healthcare delivery. Guilcher also stressed the issue of support for informal caregivers upon whom

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the formal health system relies. An informal caregiver is someone who takes care of a friend or family member without pay.

The way forward

The review's findings suggest that it is time to start piloting new models and testing them in communities to see whether they work.

A telephone help-line

Guilcher recommends that ONF, together with its partners, consider funding a pilot project for a telephone help-line, possibly with the use of video technology. The help-line could be conceived as a means of supporting informal care providers by linking them with formal healthcare providers. A telephone help-line could also assist people with SCI engage in self-management for certain conditions. (Please see *Healthcare At Your Fingertips* in this issue for a related article.)

Mobile Multi-Disciplinary Teams

Another suggestion for further ONF research is to fund a pilot project for a mobile multi-disciplinary primary care team. Such programs have proven successful both in Australia and in the United States. In these programs, the

teams visit the individuals with SCI in their communities.

Supporting Informal Caregivers

Funding the development of work shops, education resources and mentorship programs were among some of the suggestions designed to assist and support informal caregivers. Policy makers are now starting to realize the vital role informal caregiving is playing in the SCI population. Guilcher added that informal caregivers form the backbone of primary healthcare for people with SCI.

Which is the best model?

Guilcher advises that the best model would be one that maximizes flexibility. "We don't know what the best model of delivery of primary healthcare services is. That is the direction in which the research really needs to go," Guilcher said.

But which model should be tried first? Which is the best model for primary care delivery for individuals with SCI?

Guilcher answers that there is no single best model, at least not one that works for every community in every geographical region.

In a region where distance poses a problem, a telephone or

video-conferencing method of healthcare delivery or else a mobile team of specialists may be among the best models to try. But in an urban centre where there is a higher concentration of people living with SCI within a short travelling distance, a centre specialized in dealing with SCI-related health concerns might prove to be the best option.

Where should we go from here?

As part of its ongoing commitment to primary healthcare for people with SCI, ONF and the Centre for Family Medicine Family Health Team (CFFM FHT), is funding a multi-disciplinary professional clinic, under the direction of Dr. Joseph Lee, for people with mobility issues in Waterloo Region. The "Mobility Clinic" is located at: 1187 Fischer-Hallman Road, Suite 623, in Kitchener. While the Mobility Clinic is open only on Wednesday mornings, the Family Health Centre has the ability to address acute problems Monday through Friday. The CFFM FHT has also outfitted additional specialized examination rooms in its Health Sciences Campus site in downtown Kitchener at 10B Victoria Street South.

Healthcare At Your Fingertips

Primary Healthcare Delivery by phone and email

What if you could pick up the phone and speak to a qualified nurse practitioner who is experienced in rehabilitation for someone like you with a spinal cord injury (SCI)? What if you could send an email and engage in a discussion with a nurse practitioner online?

Research on access to primary healthcare has been a priority for the Ontario Neurotrauma Foundation (ONF) for over a decade. As approaches to primary healthcare take shape, it is crucial to find the best

combination of healthcare professionals and the best ways to deliver that care to individuals with spinal cord injuries. Which models of primary healthcare would best serve people with spinal cord injuries? ONF wanted to know.

Specifically ONF wanted to discover whether a telephone or email service staffed by a nurse practitioner would be welcomed by people with SCI. To find out, ONF funded a study led by Nathalie Lapierre, a Nurse Practitioner.

ONF funds research into better primary healthcare delivery models

A person with SCI commonly

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experiences secondary health conditions that can be acute and/or chronic and may require immediate attention. Often, the primary health provider, a family doctor for instance, is unacquainted with the specific health concerns confronting a person with SCI. One barrier is a knowledge gap. Another is access to primary healthcare facilities both in terms of transportation and in terms of physical barriers.

ONF wanted to hear from people with spinal cord injuries about ways to improve primary healthcare. The foundation decided to fund research into the development of a questionnaire designed to ask adults with spinal cord injury about their experience with primary healthcare delivery. 98 adults participated in the survey - 75% were men, 25% were women with a mean age of 45.

The questionnaire

In addition to collecting information about primary healthcare, the questionnaire was designed to determine interest among participants in a telephone health line staffed by a nurse practitioner. The participants were recruited for the study in collaboration with the Canadian Paraplegic Association Ontario and the Ottawa Hospital Rehabilitation Centre.

Survey Results

On average, the people surveyed had six health issues per year. The most common issues that required consultation related to the bladder (60%), pain (38%), pressure sores (31%), spasticity/joint concerns (29%) and edema (21%).



Although most people sampled indicated that many health facilities were accessible to people with spinal cord injuries, three quarters said that physical, time and financial barriers were still an issue in accessing community or healthcare resources.

One of the most revealing aspects of the study relates to the ranking of healthcare providers in terms of knowledge about SCI health issues. While 98% of those surveyed indicated that they found nurse practitioners to be "quite" or "very" knowledgeable, less than half gave a similar ranking to their family doctors. In spite of this, the most consulted healthcare provider was the family doctor! The nurse practitioner was ranked third after the family doctor and physician specialist as the healthcare provider most frequently visited in a year.

Telephone Help-line for People with SCI

95% of the participants indicated

that they would use a telephone health line staffed by a nurse practitioner with 67% indicating that an email help service would be useful.

Help-lines are not new. They are being used already to serve other groups of people. A health help-line staffed by a nurse practitioner could address gaps in healthcare delivery experienced by those in remote communities as well as those for whom transportation is a barrier. Additionally, as Nathalie Lapierre, primary investigator, notes in her conclusion: "a nurse practitioner has greater freedom to assess, diagnose, plan and prescribe" Lapierre suggested that a nurse practitioner with experience in rehabilitation would be best suited to staff a telephone health line for people with spinal cord injuries. A nurse practitioner with rehabilitation experience could also address the knowledge gap of healthcare professionals as reported by survey respondents. Lapierre also suggested that links with existing health lines, like Telehealth Ontario, should be investigated.

Moving Forward

Lapierre presented her findings at several professional conferences and her research was written up in publications for the Canadian Paraplegic Association Ontario and the Ottawa Rehabilitation Centre. A province-wide telephone service staffed by a nurse practitioner may not be on offer yet but based on the findings of this ONF-funded research, hopefully it's just a matter of time before you can let your fingers walk you back to health!

