Toronto
Acquired
Brain Injury
Network

ANNUAL REPORT
2007 - 2008

Message from the Chair and Executive Director:

Brain injury is often called 'an invisible injury' but over the past year we have been working hard to make the invisible more visible. The organizations that form the Toronto ABI Network are committed to improving the quality of life for acquired brain injury (ABI) survivors and their families and the Network, through its infrastructure and resources, has been there to support these endeavours and facilitate excellence in the provision of services.

This year we had many exciting opportunities to raise awareness about brain injury and have been working to increase the understanding of government and Local Health Integration Networks (LHINs) about the complex needs of individuals with an acquired brain injury and the policy development and planning required.

Last summer we met with the Minister of Children and Youth Services, Mary Anne Chambers, and senior members of her staff, to ask for her leadership and direction in the implementation of a coordinated, cross-ministerial approach to supporting children with ABI and their families. We were very encouraged by the obvious interest in and appreciation of the needs of this complex population demonstrated by the Minister and her staff.

We also met with the Director of the LHIN Liaison Branch, Carrie Hayward, and her staff, to highlight the needs of individuals with ABI and the need for cross-LHIN planning and coordination of services for the ABI population. This meeting also provided an opportunity to highlight the role that the Toronto ABI Network can play, through its membership, in supporting the planning and decision-making of the Ministry and the LHINs.

Malcolm Moffat
President and CEO, St. John's Rehab Hospital, and Chair, Toronto ABI Network

The Toronto ABI Network is one of the founding members of a collaborative which was formalized this year to become the Ontario Alliance for Action on Brain Injury. The Alliance and a series of public service announcements were launched at Queen's Park in the spring and have already served to draw significant attention to ABI. Through this alliance we had the opportunity to meet with staff from the Premier's Office and representatives from the Ministries of Health and Long-Term Care, Children and Youth Services, Community and Social Services, and Community Safety and Correctional Services. This meeting was critical to begin cross-ministerial discussions about the ongoing and varied needs of individuals with ABI and their families, and to the understanding that ABI is not only a health issue, but impacts other ministries as well. As a result of this meeting, we have been asked to give some preliminary consideration to what is needed in the ABI community to move forward. A follow-up meeting with the Premier's Office is scheduled for the fall.

Through our participation on various LHIN committees and advisory groups, we have raised awareness about ABI and worked to enhance understanding about the planning needed to support this group.

This year was a busy and exciting time for the Network and has also been a period of significant change: in September 2007, the Network moved its offices to Toronto Rehab's Lyndhurst Centre in Leaside; Charissa Levy, the Network's Executive Director, took a parental leave after the birth of her second child; and Judy Moir took the reins as Acting Executive Director during Charissa's absence. Despite these changes, the Network has continued to work towards reaching its strategic objectives and, due to the commitment of the many volunteers who support the Network, we have made significant gains which are reflected in the following pages.

The Toronto Acquired Brain Injury Network was established in 1995 to address issues of fragmentation in the system and inequitable access to service for individuals with an acquired brain injury. Since its inception, the Network has become a reputable and recognized voice in advocating for the needs of those with acquired brain injury.

In April 2008, we were pleased to welcome the Ontario Neurotrauma Foundation (ONF) as a member organization of the Network. Our membership has now grown from an initial membership of 11 organizations to the current membership of 22 organizations. With a shared vision, we see many exciting opportunities to collaborate with ONF and our other members. By working together we can leverage our collective resources to improve the quality of life for individuals with ABI and their families.

It can not be said enough how grateful we are to the many volunteers who make the Network as successful as it is. To our member organizations, committee members and other interested stakeholders, we offer our thanks.

Malcolm Moffat, Chair

Judy Moir, Excutive Director (Acting)

Systems Coordination

The core business of the Toronto ABI Network has always been to support equitable and timely access to services for individuals with an ABI and this year has been no exception. In fact, we have seen a significant, steady increase in the number of referrals managed by the Network over the last few years. In 2007 we set a new record for the most referrals received in one year with 903 applications received, a 20% increase over the next highest year (752 referrals received in 2006).

Referral Management and Service Coordination

Referral management and coordination of services are top of mind across healthcare today, given the Alternate Level of Care (ALC) pressures that exist in acute care and our collective desire to ensure that patients are receiving the support they need, when they need it. As a result, how patients are referred and gain access to needed services are being monitored across populations and across sectors.

There are many initiatives underway to improve referral processes, and the methods developed by the Toronto ABI Network are looked to as one of the models of effective referral management. We have been consulted by various groups about our referral process and are pleased to know that the work the Network has done over the years is being leveraged to guide others.

The Network's own referral processes have also seen some significant changes this year in order to realize further efficiencies and reduce the workload of referrers who refer patients to multiple rehab programs at different organizations (e.g. ABI, neuro, geriatric).

Working with the GTA Rehab Network, we participated in the development of a standardized referral form that can be used for referrals to most inpatient rehabilitation and complex continuing care programs. The *Inpatient Rehab/ CCC Referral Form* includes questions common to all rehab populations and has population-specific inserts for different rehabilitation populations (ABI or MSK, for example).

The Toronto ABI Network's previous application form, the *Inpatient ABI Client Profile,* was a significant resource in the development of this common, post-acute care referral form and we worked hard to ensure that the information requirements specific to ABI were not lost.

Given the overlap between acquired brain injury and many other rehab programs (e.g., neuro, spinal cord, geriatric), those making referrals through the Toronto ABI Network had much to gain by the introduction of a common form. Following the implementation of the common form, early indications point to a significant reduction in the duplication of work which can result when referrers are not certain which rehab program is most appropriate for their patient.

At the same time and closely linked to this initiative, a new process of referral is being launched across the Toronto Central LHIN, impacting many of the organizations in our membership. The Toronto Central LHIN's Resource and Referral Management System will allow clinicians to submit referrals through an online form. This has implications for the Network given our centralized wait list and we are pleased to have been able to advocate for necessary modifications to the process in order to accommodate the unique needs of ABI referrals.

Patients Being Sent Home to Wait for Rehab

Through monitoring of our centralized referral system, the Network's Systems Coordination Committee has identified an emerging concern that we felt warranted a targeted response. Transitioning patients with an ABI from acute care to inpatient rehab has been noticeably affected by consistent wait lists for rehab and limited bed capacity.

Rather than a direct transfer to a rehab centre, patients are increasingly being repatriated to community hospitals or are discharged home to wait for a rehab bed. This appears to be an issue that is unique to the ABI population, possibly due to the limited capacity of inpatient rehab beds and the perception that some ABI patients with good physical recovery can be managed at home in the meantime.

Once patients are at home, our data indicates that approximately half of these patients are declining admission to a rehab facility when a bed is offered. Families have difficulty encouraging their loved ones to go to an inpatient rehab program and/or the patient and family do not immediately recognize the need for intensive rehab. Concurrently, rehab hospitals report that patients who have been admitted from home are more likely to discharge themselves from their facilities within one or two days.

The most concerning aspect of this is that when acute care facilities discharge someone home to wait for an inpatient rehabilitation program, an assumption is made that they will get the rehab service they need through the recommended inpatient program. If the patient then refuses or for whatever reason does not access inpatient rehab, the opportunity to connect them to alternative services in a timely manner may be lost. Anecdotally, we are told that many of these people are recognizing a need for rehab after a significant period of time has passed and are struggling to regain access to the necessary services.

To address this issue, a sub-committee of the Systems Coordination Committee was formed. One of their first activities was to develop a communication tool to be given to patients and/or families in the event that they are being discharged home to wait for rehab. The purpose is to advise patients and family members why they have been referred to an inpatient rehab program and to link them with the Network, enhancing the chance that these patients will be connected to appropriate services and not become lost in the system.

The Network is also endeavouring to put follow-up measures in place to ensure that those who may refuse inpatient rehab are connected with an appropriate alternative if possible. However, this type of follow-up requires significant resources.

For this reason (along with the additional number of referrals being managed and the increase in the number of individuals requiring significant support to access the necessary services), the Network has submitted proposals to the Toronto Central LHIN and the Central LHIN to support an enhanced model of system navigation.

Education and Best Practices

The Network continued its strong focus on education and awareness this past year. Through its various committees and dedicated volunteers, the Network has been able to influence consistent and quality care across the system and support our members with the promotion of best practices and the sharing of information. From the planning of our bi-annual conference, to ongoing education about the management of agitated patients, to the continued promotion of best practices around shared treatment for those with substance use and ABI and family intervention for adolescence with ABI, this year's activities demonstrate our collective focus on influencing excellence in the services and supports for those with an ABI.

We are pleased to announce that the fall of 2008 will once again bring the Toronto ABI Network's bi-annual conference. Over the years this conference has become a nationally-recognized, important event on the calendar of many in the brain injury rehabilitation community.

Planning for the conference began in the fall of 2007 and has been ongoing. A very dedicated planning committee is responsible for leading an unprecedented sponsorship drive that is critical in supporting the conference and the ongoing activities of the Toronto ABI Network. We thank the many members of the committee for their ongoing commitment.

The program for the upcoming November 2008 conference is posted on our website at www.abinetwork.ca/conference2008

Substance Use and Brain Injury Project

Representatives from the Toronto ABI Network's Best Practice Committee collaborated earlier this year on the Substance Use and Brain Injury (SUBI) project, an initiative led by Community Head Injury Resource Services (CHIRS) and the Centre for Addiction and Mental Health (CAMH). The purpose of this initiative is to facilitate ongoing interdisciplinary management of clients living with both an acquired brain injury and problematic substance use.

The objectives of the project were to:

- Develop initial treatment alternatives for ABI clients whose cognitive impairments precluded their treatment in mainstream substance use programs;
- Provide support to CAMH in managing cognitive impairments presented by clients with brain injury;
- Facilitate training between CHIRS and CAMH; and
- Provide prevention and secondary prevention materials to clients with ABI.

The project resulted in the development of a series of materials to facilitate the vision of increased access to specialized addictions services for people living with brain injury, including:

- a manual for brain injury providers and substance use providers;
- a workbook for clients (to be used by clients and their providers);
- a pamphlet for clients entering the system with brain injury in acute care settings; and
- recommendations for screening, prevention and education to be used in acute care and/or rehab settings.

The role of the Best Practice Committee was to support the dissemination of the findings of this initiative. As a first step, the Network's Best Practice Committee hosted a stakeholder education session at the end of October to provide an overview of the SUBI project and to facilitate a discussion about implementation within organizations. The committee is considering other mechanisms to maintain and expand the reach of this initiative.

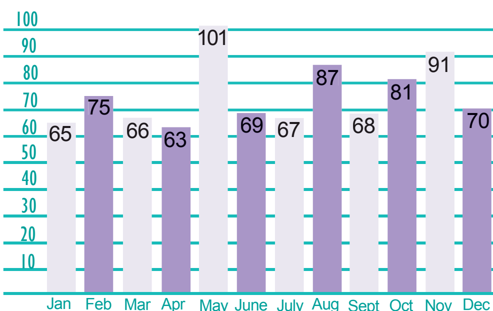
As a direct outcome of this initiative, the Best Practice Committee is investigating other opportunities to support the education of providers in other areas (e.g., ABI and suicide risk assessment and prevention, and family intervention for youth and adolescents with ABI).

Communications Update

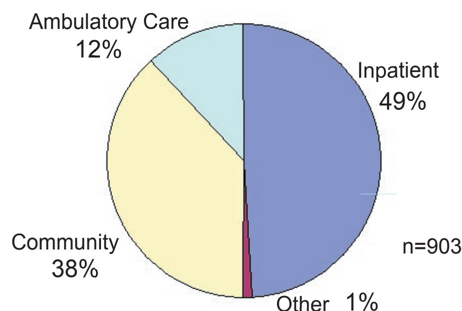
After 42 issues spanning just a little more than a decade, *ABI Update*, the quarterly newsletter of the Network, is now being developed and distributed as an electronic-format newsletter. By moving to an online format, readers of *ABI Update* will be able to quickly go to the stories that interest them.

We are very pleased to note that over the years, *ABI Update* has become a valuable resource for professionals in the ABI community and other interested stakeholders. From a list of 233 people in April 1997, to whom we mailed a printed version of our newsletter, we have grown to a subscription base of 1,063 people who receive the newsletter regularly by email.

Client Data Tracking/Reporting



* TOTAL NUMBER OF REQUESTS FOR SERVICE RECEIVED BY THE TORONTO ABI NETWORK (JANUARY 1, 2007 - DECEMBER 31, 2007)



* TOTAL NUMBER OF REQUESTS FOR SERVICE RECEIVED BY THE TORONTO ABI NETWORK (JANUARY 1, 2007 TO DECEMBER 31, 2007)

* TOTAL NUMBER OF REQUESTS FOR SERVICE RECEIVED BY THE TORONTO ABI NETWORK DURING THE YEARS SPECIFIED

Restraint Forum

Over the last 18 months, the System Coordination Committee has been investigating the use of restraints and observers in acute care and the impact this has on transitioning people into rehabilitation. In May 2006, a group of clinical providers attended a workshop addressing the use of restraints within hospital settings. The workshop, entitled *"The Restraints Dilemma"*, highlighted current practices within various healthcare organizations and also addressed possible solutions or directions to reduce the use of restraints to help prepare patients for rehab.

As a result of this initial meeting, a small working group began working on the development of a resource guide to assist individuals and organizations in the management of agitated patients and to facilitate the transition of these patients from acute care to rehabilitation. Stakeholders were brought back together in January 2008 to investigate changes that had occurred in hospital practice since the first workshop.

As a result of this activity, the *Professional Resource Guide on the Use of Restraints*, developed by a sub-committee of the Systems Coordination Committee, was launched and is now a feature on our website.

View *Professional Resource Guide* at: www.abinetwork.ca/profresourceguide

ABI Rehab Definitions Initiative

The Toronto ABI Network is collaborating with the GTA Rehab Network in a major initiative to standardize the core components of publicly-funded rehabilitation across the care continuum.

The Rehab Definitions Initiative has strong participation from across the member organizations of the Toronto ABI Network and endorsement from the ABI Advisory Committee. The initiative was undertaken in response to consistent stakeholder feedback that the wide variety of rehabilitation programs and services across organizations is a source of confusion and frustration.

The type of services, degree of specialization and frequency and duration of therapy can vary significantly from one rehabilitation program to another. The result is often uncertainty about where to make referrals and results in delays for patients. In addition, the lack of consistency makes it difficult to measure and compare patient outcomes between programs at different organizations or to plan effectively across the system.

In the initial phase of the project, staff from the GTA Rehab Network worked with representatives from its membership to develop a generic framework and definitions that describe the key components of rehab in each setting.

The Toronto ABI Network has worked with our own member organizations to facilitate the process of adapting this generic framework for the acquired brain injury and neuro rehab populations using best-available evidence.

Based on the completion of the framework for ABI/neuro rehab populations, a self-assessment tool has been distributed to organizations to aid in evaluating their programs against the established definitions/standards. Respondents have been asked to report on whether they fully meet, partially meet, or do not meet individual definitions.

The results of this survey will allow organizations to determine how well they are meeting the evidence-based standards and help identify quality improvement initiatives. The results will provide all of us with a clearer picture of the current state of ABI rehab across the Network's membership and within individual LHINs, enabling organizational and system-wide advocacy for the necessary resources to ensure timely access and equitable standards of care.

Toronto Acquired Brain Injury Network
520 Sutherland Drive, Room B59
Toronto, Ontario M4G 3V9
Tel: (416) 597-3057 • Fax: (416) 597-7021
info@abinetwork.ca • www.abinetwork.ca

Member Organizations

The membership of the Toronto ABI Network is comprised of publicly-funded organizations providing ABI service or support in Toronto and the surrounding area.

- Baycrest
- Bloorview Kids Rehab
- Brain Injury Society of Toronto
- Bridgepoint Health
- Central Community Care Access Centre
- Community Head Injury Resource Services of Toronto
- COTA Health
- Head Injury Association of Durham Region*
- The Hospital for Sick Children
- Lakeridge Health
- Ontario Ministry of Health and Long-Term Care*
- Ontario Neurotrauma Foundation*†
- Peel Halton Acquired Brain Injury Services
- St. John's Rehab Hospital
- St. Michael's Hospital
- Sunnybrook Health Sciences Centre
- Toronto Central Community Care Access Centre
- Toronto Rehab
- Trillium Health Centre
- University Health Network
- University of Toronto*
- West Park Healthcare Centre
- York Central Hospital

* *ex-officio member*
† *member as of April 2008*

Toronto ABI Network Secretariat

Judy Moir *Executive Director (Acting)*

Charissa Levy *Executive Director (on leave)*

Patty Aird *Office Manager*

Robert Jessop *Communications/Data Coordinator*

Linda Milan *Data Entry Clerk*

Cora Moncada *Assistant Executive Director (Acting)*

All staff are shared with the GTA Rehab Network.