

NeuroMatters

Connecting YOU to the Research

Filling in the Gaps

Psychological services and Acquired Brain Injury in Ontario

In the Winter 2011 issue (No. 13), we reported on an Ontario Neurotrauma Foundation (ONF) funded *Systems Analysis of Acquired Brain Injury Services in Ontario*. That study identified a sector that is especially underserved: people with an ABI who have a co-existing mental health condition.



Among the most significant problems identified by the Systems Analysis was, that mental health services for people with acquired brain injury (ABI) are simply lacking. An individual with ABI and a co-existing mental health problem is unlikely to receive coordinated care. Neither healthcare service has the expertise to provide comprehensive treatment. Without coordinated care, the needs of people with ABI who have a mental health concern continue to

go unmet, increasing the risk of going into crisis, which in turn can lead to frequent emergency room visits, hospital admissions, increased homelessness and even incarceration. But it doesn't have to be that way.

With more coordinated and thus effective services, fewer people are likely to fall through the cracks of the healthcare system, resulting in fewer unnecessary hospitalizations and generally less burden on the healthcare system.

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Ontario Neurotrauma Foundation
Fondation ontarienne de neurotraumatologie

A more stable and better cared for population could free up resources to invest in improving quality of life instead of crisis management.

The Systems Analysis pinpointed several ways in which services for people with ABI and mental health conditions could be improved:

- greater support for clients in the community
- greater coordination between different service agencies
- coordinated care for people with ABI who have a co-existing mental health condition
- increased collaboration between mental healthcare professionals and ABI healthcare professionals

In response to that study, ONF called for proposals that would address the gaps identified by the Systems Analysis. In this issue, we report on the progress of two ONF funded projects on mental health and ABI that emerged in response to the Systems Analysis.

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1. MENTAL HEALTH AND ACQUIRED BRAIN INJURY: A SYSTEMS APPROACH IN BRANT

Detailing the current situation

One ONF-funded project is being piloted in the Brant area of the Hamilton Niagara Haldimand Brant (HNHB) Local Health Integration Network (LHIN). The Brant area was chosen because it utilizes the services of the Hamilton Health Sciences and St. Joseph's hospitals in addition to the Brant area resources. Brant covers a vast rural area of 22 communities, among them communities of the First Nations people of the Six Nations and New Credit Reservations.

"Here in Brant, there is a lack of a coordinated system or service pathway for individuals who experience the effects of both an acquired brain injury (ABI) and mental health illness," confirmed Veronica Pepper, Project Lead of *"Piloting the Process of Systems Change Through Collaboration Between the Mental Health and Acquired Brain Injury Sectors in Brant"*. According to Pepper, neither sector is in a position to meet the needs of this complex population.

In contrast to the rest of the province, the Neurobehavioural Program of the Hamilton Health Sciences ABI Program has a six-bed inpatient facility specifically developed for dually diagnosed ABI/mental health patients. "But there are only six beds in the entire province that are designed to serve patients with a dual diagnosis. These six beds are provincial beds meaning that people from across the province have access to them," Pepper said, adding that there is a six to eight month wait for the provincial beds. "Furthermore, when patients leave the hospital and return to their families, there is no community-based ABI-mental health support," she said. The lack

of coordinated follow-up care means that gains made in hospital are often lost upon return to the community.

In extremely complex cases, a patient would be referred for a highly customized treatment and support plan administered by the province. But this made-to-order service is neither practical nor financially sustainable and the province is moving away from this form of care in favour of a plan that could serve all individuals with ABI and a co-existing mental health problem.

According to Pepper, in some regions of the province, having an ABI actually disqualifies a person from access to mental health services, leaving a person with a dual diagnosis with little in the way of specialized care. "What we need is a consistent and coordinated system," Pepper said.

What a better system might look like

ONF recognizes that the key to success is creating effective partnerships across sectors. A coordinated service depends on existing organizations collaborating to achieve a common goal: a comprehensive service for people with ABI and a co-existing mental health concern.

Pepper is the HNHB ABI Services and Systems Navigator for the HNHB ABI Network. For this project, she is fostering collaboration among healthcare professionals and healthcare managers drawn from both the brain injury services sector and the psychiatric services sector.

Having identified key stakeholders and policy makers in the region, Pepper is building cooperation and interest across the sectors both by promoting her role as Systems Navigator, and by soliciting interest and commitment from various agencies. Following a detailed analysis of how the

"What we need is a consistent and coordinated system"

system in Brant is currently serving clients with both ABI and a mental health concern, Pepper and her collaborators will create and then implement an action plan, assess its success and then determine how the process could be applied in other regions and ultimately to other sectors. Once the plan is in place, she envisions healthcare professionals from either sector being invited to consult on cases in which both brain injury and psychiatric issues are apparent, whether in the Emergency Room, in the clinic or in the community.

The path has been planned but it's not always smooth. Pepper reports that she has been encountering some resistance to the idea that coordinated services are necessary. "Mental health providers often don't realize that many of their patients may be people with ABI. Similarly, the ABI sector has patients with mental health issues who may not be so identified. We're trying to educate both sides," Pepper said.

Looking ahead

If the project in Brant is successful, individuals there who experience concurrent ABI and mental health issues can look forward to coordinated treatment, services

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and support. Because the process involves coordinating already existing resources with no new funding or resources, the system could be sustainable over the long term. And when people with ABI and a mental health condition are better cared for, not only will they need fewer emergency resources, but the likelihood of being able to remain in the community in their own homes also increases.

The model of coordinating services implemented by Pepper and her team could be established in other areas of the HNH B LHIN, as well as in other regions of Ontario. In fact, Pepper and her team may well be developing a method with application in a variety of health sectors including addictions, geriatrics, adolescence and developmental services.

2. PILOTING A PARTNERSHIP TO DELIVER COORDINATED ABI & MENTAL HEALTH SERVICES

ONF is also funding a pilot project designed to test a specific partnership between an acquired brain injury (ABI) delivery service and a mental health delivery

service. The partnership is between Community Head Injury Resource Services (CHIRS), an ABI service agency, and Reconnect, an Assertive Community Treatment (ACT) Team that serves people with mental health concerns. Both organizations are based in Toronto where the project is being conducted under the direction of project lead Carolyn Lemsky, Clinical Director of CHIRS. With this project, ONF is not funding service delivery, but rather a pilot that seeks to coordinate care between existing healthcare services.

CHIRS is a community-based provider of Acquired Brain Injury services. Formerly known as Ashby House, CHIRS was founded in 1978 as the first community-based brain injury rehabilitation program in North America. From its origins as a transitional group home, CHIRS evolved into a multi-service agency providing a broad range of supports for people with ABI including a variety of supported living opportunities and community support and programs for individuals who are able to live more independently. Designed to assist people with mental health issues, Assertive Community

Treatment (ACT) teams are built on a community-based, client-centred care model with a recovery-based focus. The model is based on one that was developed in the US in the 1980s for those individuals with multiple and complex diagnoses who benefited from services offered in the community.

ACT teams are specifically designed to work with people who have serious mental illness. Early research clearly demonstrated that ACT teams were successful at improving clients' functional outcomes, in terms of maintaining stable housing and showing greater independence in daily life. Subsequent research suggested that sticking closely to the standardized model is essential to success including reduced psychiatric admissions and increased community integration. Reconnect is a mental health agency that runs a variety of programs including an ACT team.

When individuals with an acquired brain injury and a co-existing mental health condition seek healthcare, they tend to be served by one or the other system but rarely receive integrated care. "It's the luck of the draw which label they receive and which service system they wind up in. When psychological problems are most prominent, they tend to wind up in the mental health system, and when there's a lot of physical impairment in addition to the neuro-behavioural impairment, it's my impression that they end up in the ABI rehabilitation sector," Lemsky said.

Lemsky acknowledged that there is some integrated care occurring, but added that it's not available to the majority of clients. In fact, an ABI diagnosis is an exclusionary criterion in the screening process for most ACT



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teams in the province, meaning that people with ABI might be automatically excluded for service. Despite that, it is likely that most ACT teams have people with an ABI on their rosters, either because the brain injury was not diagnosed at the time of the screening or because the brain injury occurred after intake into the program.

One of the major findings of the Systems Analysis of ABI services was that community support was lacking. Both these agencies work with clients in the community and so are well positioned to forge integrated community support for clients with ABI and mental health concerns. The primary focus of the project is to address the education needs of both service teams. The ACT team will provide CHIRS with education on the diagnosis and management of mental illness and the CHIRS team will provide education on the diagnosis and management of brain injury. The pilot study will provide integrated care to five clients, who were recommended by both CHIRS and by the ACT agency from among existing clientele.

"A big piece of it is that once you provide the education, both service systems recognize that



they are already serving people with both conditions," Lemsky said, drawing on her experience establishing coordinated services for people with ABI and addiction. "Once they realize that we are only helping them deal with problems they are already seeing, they become more comfortable with the target population and much more willing to learn how to support these clients," she added.

ACT teams deliver 75% of their care in the community, i.e. not in a clinic or hospital. "Ultimately, we want to help the ACT teams realize that they can accept and acknowledge brain injury and remain faithful to the service delivery model. We want to help them work a little smarter with the brain injury. We hope to make them less reluctant to take clients with acquired brain injury and eventually to encourage them to eliminate brain injury from their exclusionary criteria," Lemsky said.

Another part of the education is learning to identify the symptoms of the co-existing conditions. Some brain injury impairments can resemble major psychiatric disorders and the reverse is also true. "You can develop a loose

thought process that looks a lot like psychosis. And you can sometimes develop symptoms from ABI that look like obsessive compulsive disorder," Lemsky explained. Part of the cross-education will be aimed at helping the teams identify symptoms of either condition.

Looking forward

This pilot project is in the first stages of completion. In addition to the cross-education, Lemsky envisions an approach that might see consultations from each agency on the other agency's teams where appropriate. The project is ongoing with a target completion date in 2013.

ONF anticipates that these two pilot projects will have broad impact demonstrating that services for people with co-existing ABI and mental health issues can be coordinated in a way that better serves and assists clients, while enabling organizations to be more effective and inclusive, and improve system efficiency. If the projects are effective, each team will be working with ONF to identify the key components to a successful application on a larger scale.

"once you provide the education, both service systems recognize that they are already serving people with both conditions"

Coming of Age

Youth and Acquired Brain Injury



The Ontario Neurotrauma Foundation (ONF) supports research that improves the health and quality of life of all people with an acquired brain injury (ABI). Youth are no exception. Even before the Systems Analysis for ABI demonstrated that children and youth are an underserved sector, ONF decided to support *A Longitudinal Evaluation of the LIFEsan Model of Linked Healthcare*, aimed at helping young people successfully undergo that all important transition from pediatric to adult healthcare services. ONF is supporting the program by funding the evaluation.

The Gap

Coming of age can be challenging. For someone with a chronic health condition, a smooth transition to adulthood involves learning how to navigate the adult healthcare system. In Ontario, transition preparation on the pediatric side is uneven across the province; in most cases, preparation is virtually absent. Children with ABI are not expected to navigate the healthcare system; it's done for them by parents and healthcare providers. But for adults it's a different story. Too many young adults with early-onset ABI enter the adult system without the required skills to ensure continuity of care and support. And lack of preparation is also apparent on the part of service providers. Complicating the issue further is the fact that the eligibility criteria for some adult care service models disqualify adults with childhood-onset ABI. "The experience of

transitioning from pediatric care to adult care can be like falling off a cliff," said Shauna Kingsnorth, co-investigator on the LIFEsan transition evaluation.

A shortage of family physicians and a lack of specialized expertise regarding the late effects of childhood disabilities has led to a situation in which few practitioners seem willing to take on these clients. As a consequence, many adults with childhood onset disabilities continue to receive services from pediatric health centres, or worse, they receive no specialized services at all. Neither situation is desirable and both have serious long-term effects on the health and well-being of youth with ABI.

The evolution of the model

The current LIFEsan project was initiated on the heels of a limited pilot that tested the waters. On the

strength of the success of the initial pilot, the Toronto Central Local Health Integration Network (LHIN) funded a full model of the transition program. ONF came on board to fund the evaluation, acknowledging that there is much to be learned from this approach. The evaluation will assess the impact on the first group of clients to pass through the full model of the transition program.

The unique aspect of this LIFEsan model is that it engages partners on both the pediatric and adult sides. The transition process is an ongoing, dynamic one as clients prepare for discharge from pediatric care. The project goal is to provide continuity of care that is coordinated between the pediatric and the adult services. "Transition is a hot topic," Kingsnorth said. "We're still defining

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it. It involves self-determination, self-efficacy and self-management."

The transition program is set up for children with one of two conditions: ABI and cerebral palsy. Thirty young people with ABI have volunteered to participate in the evaluation project. They are being asked to join when they are 17 years of age with the evaluation collecting information about them from the time of their 16th birthday until their 19th birthday. Two slightly different versions of the model are being tested. Clients with CP are being streamed into a pediatric LIFEsplan clinic; whereas, clients with ABI receive LIFEsplan transition preparation within their existing pediatric clinic. In both versions, clients receive two years of preparation before gaining entry into the adult LIFEsplan program, where the care is lifelong. Part of the work of the evaluation will be to compare and contrast the two models of transition.



The experience of transitioning from pediatric care to adult care can be like falling off a cliff

The ONF evaluation will follow the clients through the two year transition preparation period as well as for one year after the point of transfer. ONF is interested in both the outcome evaluation, i.e. how the clients fare with their transition to adult services using this model, as well as the process evaluation of the program, which looks at what elements are key to implementing it, by whom, and when. It is ONF's hope that the evaluation might be used to discuss the potential of a project like this with other Local Health Integration Networks where transition services for children and youth are lacking.

"We don't know yet what the gains of this model are. We're hoping to learn that from the evaluations we are doing. There is very little work in this area and ONF is at the forefront of evaluating this innovative initiative," Kingsnorth said. The project is due to be completed in 2013.

ONF launches NeuroMatters Blog!

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Today!

The Ontario Neurotrauma Foundation is committed to keeping you informed about the research it supports in the areas of spinal cord injury and brain injury.

- Featuring material from the print edition plus link to related sites and back issues
- Join the NeuroMatters online community by visiting the blog at: www.neuromatters.org
- And don't forget to bookmark the ONF website where you'll find news about ONF initiatives as well as information about ONF's partners and so much more! www.onf.org

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Living the Healthy Life (continued)

What could a client expect from a workshop?

Participants arrive with a completed pre-workshop evaluation that Freitas sends them upon registration. In the first week, they receive a copy of the book *Living a Healthy Life with Chronic Conditions*, which they may keep. "We give them growth work instead of homework," Freitas said, noting that participants can refer to the book to review material covered in the workshop.

Introduced to a variety of techniques including meditation, guided imagery, muscle relaxation exercises, breathing exercises and

positive thinking, participants are also encouraged to set goals for themselves. Goals might include:

- getting outside the home for twenty minutes two or three times a week
- arm exercises
- choosing healthy snacks

"We want them to be successful in achieving their goals; therefore, we encourage them to make an action plan that they are confident they can accomplish. We review plans weekly, using problem solving and brain

storming techniques to help them overcome obstacles. Problem solving is one of the most important skills in self-management," Freitas said.

Looking Ahead

The project is in the final stages in terms of funding, but Kras-Dupuis intends to keep the program running at Parkwood beyond the funding dates. "The ONF funding helped us to establish the program to figure out what works and what doesn't work. This was an excellent start," she said.

Upcoming Events

Acquired Brain Injury Provincial Conference "The Art of Living... Life After Brain Injury"

November 2 – 4, 2011, Sheraton on the Falls, Niagara Falls, ON. For more information, please visit: http://www.obia.ca/index.php?option=com_content&view=article&id=105&Itemid=241

Taking Charge of your Health: Living Well with Chronic Pain

November 7, 2011, MaRS Auditorium, 101 College Street, Toronto, ON 10:00am – 1:00pm. Keynote Speaker: Dr. Sandra LeFort, Memorial University, Topic: Chronic Pain Self-Management Program. For more information and to register: email@actionontario.ca

Pain Management Conference – Pain Management across the Continuum: Bridging the Gap from Acute Care to Rehabilitation and into the Community

November 18, 2011, Hyatt

Regency, Toronto, ON. This conference will help you acquire a better understanding of the complexities of pain assessment and management, increase your repertoire of strategies for managing pain in various populations, and provide you with insight to apply a best practice framework to pain assessment and management. For more information:

<http://www.torontorehab.com/Events/Corporate-Events/Pain-Management-Across-the-Continuum-Bridging-the.aspx>

Rick Hansen 25th Anniversary Relay

will be in Ontario **October 28, 2011 – January 17, 2012**. "Difference Makers" teams will be Medal Bearers for the relay as part of the celebration. The Difference Makers are examples of everyday heroes who are committed to making an impact so there is an accessible and inclusive world for

all. To be engaged in this exciting landmark event, go to: www.RickHansenRelay.com

Interdependence Conference and Exposition:

May 15 – 18, 2012, Vancouver, BC. As part of the 25th Anniversary of Rick Hansen's legendary Man In Motion World Tour, the Rick Hansen Foundation and the Rick Hansen Institute are co-hosting a global conference and exposition to inspire collaboration in the pursuit of a more healthy and inclusive world. Through its unique design, *Interdependence 2012* promises to engage leaders and influencers from around the world and provide an impetus to accelerate progress towards accessible communities for all and a cure for paralysis after spinal cord injury. For more information and to register: <http://www.rickhansen.com/en-ca/home/interdependence2012.aspx>

Living the Healthy Life

Learning how to self-manage life with a spinal cord injury

The Ontario Neurotrauma Foundation (ONF) is evaluating an innovative and exciting program designed to enhance self-management skills and build confidence for people with spinal cord injuries and other chronic health conditions.



Participants in the *My Life, My Health* workshop program.

My Life, My Health

The *My Life, My Health* workshop program offered at Parkwood Hospital in London, Ontario is based on a chronic disease self-management model developed at Stanford University, California. *My Life, My Health* is designed to help participants with a chronic condition gain more confidence and control managing challenges like pain, fatigue and emotions. It also helps participants develop effective communication and problem solving skills, and healthy eating habits. In addition, participants learn how to set achievable personal goals.

My Life, My Health consists of six weekly sessions of two and half hours each. People treated at Parkwood are invited to participate, with the expectation that they will share their experiences and contribute to the sessions. They have the option to take part on their own or together with their care-givers or family members.

"People who came were

convinced of the value of the program. All have found it beneficial, especially in terms of confidence levels. They have more confidence, and less stress. They're better at problem-solving and setting goals for themselves. They are also better able to handle things when they don't go as expected," said Rose Freitas, project assistant and workshop leader. In addition to being a workshop leader, Freitas is also a graduate of the program.

Fine-tuning the Program

To help the project leads determine what does and doesn't work, each participant is asked to complete three evaluations: one before the workshop begins and two afterwards, at six weeks and then again at three months. "The evaluations give us an idea of how the participants are doing, and whether they're continuing to use some of the tools they've been given," Freitas said. Through feedback from the evaluations and

on the strength of their own observations, the project leads are able to customize aspects, like recruitment criteria.

Recruitment

Initially, recruitment was targeted toward inpatients. "Inpatients may not see themselves as having chronic, life-long conditions. They are often not yet focussed on how they will manage their condition beyond discharge," said Anna Kras-Dupuis, clinical nurse specialist and project lead. She added, "As inpatients they are still in the adjustment period."

While outpatients were better positioned to appreciate the value of the workshops, sometimes they too encountered barriers to participation, including fatigue and transportation issues.

Freitas explained that the project leads adjusted their recruitment strategy by focussing on the program's value as reported by its graduates.

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