

NeuroMatters

Connecting YOU to the Research

Forming Alliances

Addressing delivery of Spinal Cord Injury Healthcare and Community Services in Ontario

Currently, about 17,000 people with spinal cord injuries (SCI) live in Ontario.¹ It has been estimated that the healthcare costs required to support someone with a traumatic SCI over his/her lifetime can range between \$1.6 million and \$3 million.² Each year in Ontario approximately 600 people sustain an SCI, which costs the Ontario government \$1.3 billion. Evidence suggests that the rate of non-traumatic SCI is increasing as well.

While recovery from injury can take between two and three years, often the journey is not a smooth one, causing additional pain and suffering to individuals and their families. The healthcare system for Ontarians with SCI is a patchwork of services that vary from region to region. There are often ongoing obstacles to obtaining community-based home healthcare including attendant services, accessible housing and transportation. This disarray of services presents challenges and barriers to effective recovery that can result in prolonged dependence and avoidable long-term, secondary medical complications. In addition, with a prolonged recovery process and poor long-term outcomes for people with SCI, Ontario incurs increased costs to the province's healthcare and social system.

In 2007, the Ontario Neurotrauma Foundation (ONF) together with the Canadian Paraplegic Association (CPA) Ontario www.cpaont.org and the Rick Hansen Institute www.rickhanseninstitute.com

began initiatives to create strategic partnerships with researchers, service providers, policy makers, healthcare funders, people living with SCI, and provincial stakeholders to come up with a better way to address priority areas encountered by people with SCI throughout the continuum of care from injury onset through acute care rehabilitation and return to the community. The result was the creation of the Ontario SCI Solutions Alliance. In 2009, Michael Johnson was hired to lead this organization as its Executive Director.



Mike Johnson, Executive Director,
Ontario SCI Solutions Alliance

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What is an SCI Solutions Alliance?

In a nutshell, an SCI Solutions Alliance is a group of SCI experts. It's a group of people with professional and/or personal experience with SCI dedicated to improving quality of life for people with SCI by assisting in solving specific problems encountered by individuals in the province. Because they are stakeholders from various sectors of SCI research and health care services, the members of the Alliance together can strategize a means of effectively solving an individual's problem. But that's not all the SCI Solutions Alliance does. It also works on system-wide issues, again drawing on the diverse expertise of its members to address province-wide problems which individuals with SCI face while navigating the health care, institutional and community based services.

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In other words, the Ontario SCI Solutions Alliance is a client-focused and evidence-informed system that seeks to support people with SCI across the province from the time of injury through to the time that they rejoin their communities as full participants. The support comes in two forms: personalized, individual solutions and system-wide solutions. Individual needs can include, for example, getting an accessible supportive housing unit, attendant services at home or assistive devices such as a power wheelchair. Whereas system-wide support includes advocating on behalf of people with SCI for more accessible housing units, more hours of attendant services to live at home and access to primary and specialist care.

The Ontario SCI Solutions Alliance is one part of a larger SCI Solutions Model that is national in scope and provides leadership in the SCI community across the country. The Ontario SCI Solutions Model incorporates the regional alliances in Hamilton, London and Ottawa. These alliances in turn coordinate with CPA Ontario's regional service coordinators who bring issues forward to the Alliance to ensure that their clients with SCI get the best possible service available in their area. Thus CPA

Ontario and the Solutions Alliance work collaboratively in aligning and co-ordinating access to needed goods and services in the community.

Providing solutions to individuals with SCI

The regional alliances are more involved than the Ontario SCI Solutions Alliance in providing customized solutions at a local level for clients with SCI. If a person living with an SCI in Niagara region, for example, was not getting the community care he or she needed, that person could approach the CPA Ontario Regional Services Coordinator in his or her area. The CPA Ontario Regional Services Coordinator could in turn approach the Hamilton Niagara Haldimand Brant (HNHB) SCI Solutions Alliance Coordinator to seek assistance in solving the individual's problem. The HNHB SCI Solutions Alliance Coordinator would listen to the issue and then would discuss possible solutions with the other members of the Alliance. Each of the members on that regional alliance would have intimate knowledge about how various parts of the healthcare and support systems work in that region. Collaborating as a team, the HNHB SCI Solutions Alliance would come

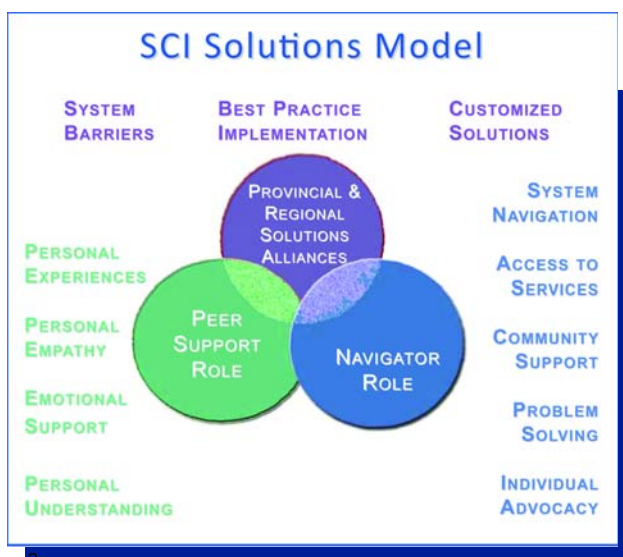
"The regional alliances provide individualized solutions for clients with SCI"

up with a solution tailored to resolve that person's particular issue. "The regional alliances provide individualized solutions for clients with SCI," Johnson said.

Providing province-wide solutions

The Ontario SCI Solutions Alliance meanwhile works to coordinate system-wide improvements in areas identified by the regional alliances. Johnson gave the example of primary care. "In each of the regional alliances, access to primary care has been identified as a recurring problem. So that issue, being common to each alliance, would be funnelled up to the Ontario Solutions Alliance priorities," Johnson said. At the Ontario level, the Alliance would seek to strategize a provincial solution, possibly suggesting changes to policies with regard to primary care for all of Ontario.

Under Johnson's direction, the Ontario SCI Solutions Alliance collects information from professionals and people with SCI, both within the Alliance and beyond it, to identify the unmet needs of people with SCI. Working groups form around various identified issues to match skill-sets of Alliance members with relevant issues so that the most important unmet needs of people with SCI can be addressed effectively. The current working groups include the Access to Primary Care Issue Working Group and the Respiratory Support Strategy Issue Working Group.



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The vision of the Ontario SCI Solutions Alliance is that people with SCI in the province will benefit from this two-pronged approach. Specifically, the Ontario SCI Solutions Alliance has identified the following goals for Ontarians with SCI:

- a decrease in the incidence and severity of traumatic and non-traumatic SCI
- life-long health, independence and full community participation
- timely access to services that meet emerging needs over each person's lifetime
- barrier-free access to "welcoming communities"
- minimize social and economic impact as a result of SCI in Ontario.

The Alliance concept has been embraced by Ontario SCI stakeholders who share a common desire to improve the lives of those living with SCI. Much has been accomplished within this structure as it continues to develop and grow. Johnson states, "I very much look forward to tapping into some of the potential that exists from working in collaboration rather than in isolation."

Footnotes:

¹ A. Farry, D. Baxter, V. Noonan et al. 2010: "The Incidence and Prevalence of Spinal Cord Injury in Canada: Overview and Estimates Based on Current Evidence". The Rick Hansen Institute and the Urban Futures Institute. <http://www.rickhanseninstitute.org/images/stories/sci-in-canada-13dec10.pdf>

² Hans Krueger & Associates 2010: "The Economic Burden of SCI: A Literature Review & Analysis". Hans Krueger and Associates. June 17th, 2010. [http://www.krueger.ca/downloads/\\$SCIReportFinal.pdf](http://www.krueger.ca/downloads/$SCIReportFinal.pdf)

Knowledge Mobilization Series Notes

The Knowledge Mobilization Series (KMS) is a platform to share ONF research, primarily with consumers and other community partners including health care providers. KMS is hosted by a partnership between Canadian Paraplegic Association (CPA) Ontario and Ontario Neurotrauma Foundation. Currently KMS takes place three times a year in different cities across Ontario, most recently, on November 5th in Thunder Bay. The meeting was well attended by 65 consumers and service providers.

The topics covered were

management of neurogenic bladder and skin care after spinal cord injury. The audience had time to interact with speakers and ask questions. We plan to go back next year to Northern Ontario to share our research with First Nations communities where opportunities for knowledge mobilization are limited or non-existent.

The next KMS is being planned for March 2011 in Mississauga and the topic for presentation and discussion is management of neuropathic pain after spinal cord injury.

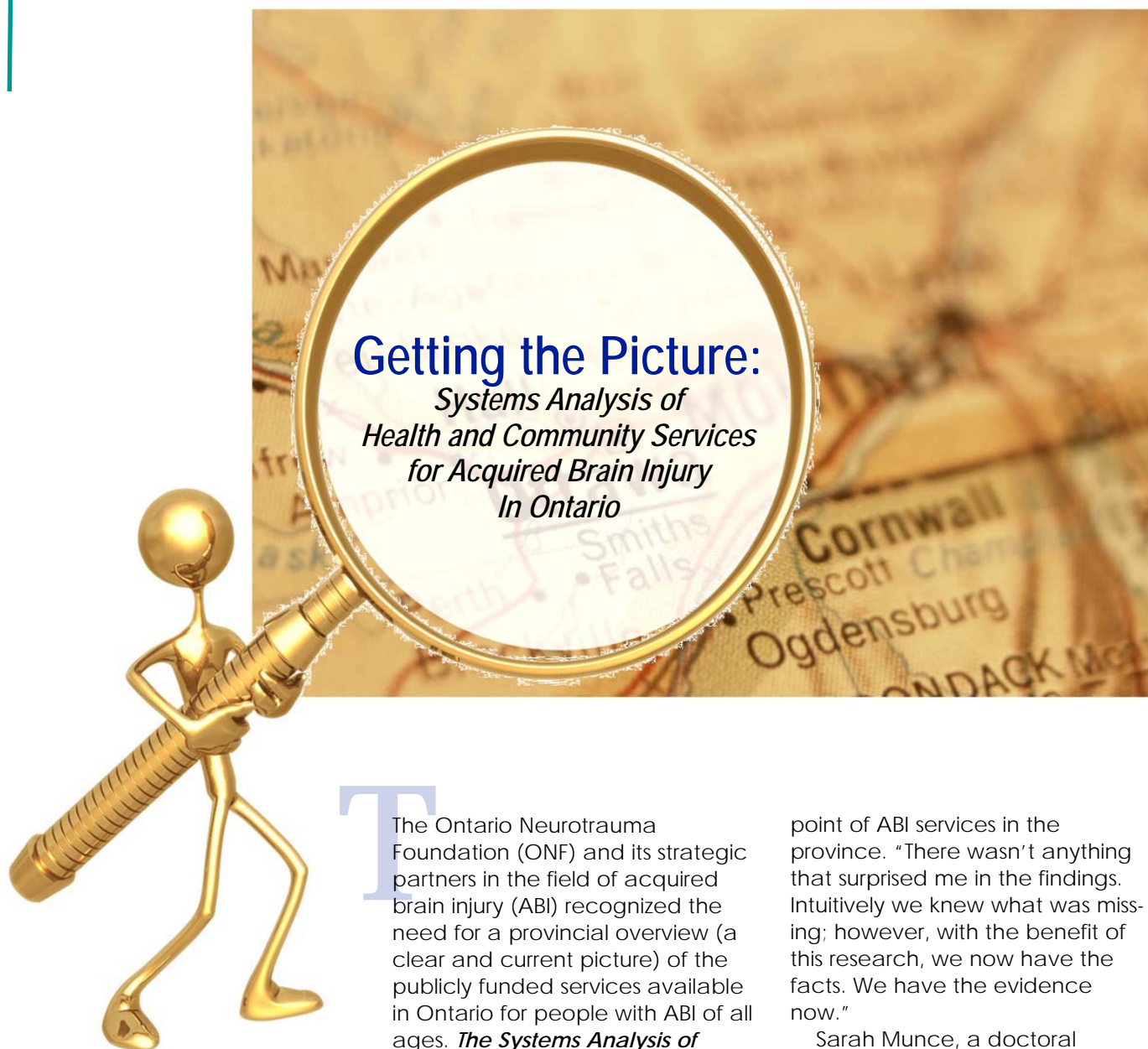
4th National SCI Conference Notes

The 4th SCI Conference was held at beautiful Niagara Casino Resort October 28-30. The conference was well attended by more than 400 delegates including invited speakers, researchers, clinicians and most notably consumers. Besides showcasing their own work, the research community discussed in great detail some of their salient research findings with consumers. The SCI consumers from all over the country were selected to attend the conference and were

financially supported by ONF and the Rick Hansen Institute (RHI). The consumers take the information gained back to their home communities and share it with other consumers and health care service providers. This conference provides a great resource for networking and keeping abreast of new research in SCI and its future applications and directions.

We look forward to the next conference in 2012 in Toronto.

by Tara Jeji, ONF Program Director, SCI



Getting the Picture: Systems Analysis of Health and Community Services for Acquired Brain Injury In Ontario

Until recently, the picture of the health and community services for people with acquired brain injury in Ontario was incomplete. Like the vision of a partially sighted person, some parts of the overall picture were quite clear, other parts blurry, still others were simply missing.

The Ontario Neurotrauma Foundation (ONF) and its strategic partners in the field of acquired brain injury (ABI) recognized the need for a provincial overview (a clear and current picture) of the publicly funded services available in Ontario for people with ABI of all ages. *The Systems Analysis of Health and Community Services for Acquired Brain Injury in Ontario* was a province-wide study to identify and examine the gaps in health and community services for people with ABI. The analysis started in April 2009 and was completed this past July.

"This was a mammoth project," said Rika Vander Laan, one of the consultants on the project. Vander Laan served for seven years as Executive Director of the Toronto Acquired Brain Injury Network affording her a unique vantage

point of ABI services in the province. "There wasn't anything that surprised me in the findings. Intuitively we knew what was missing; however, with the benefit of this research, we now have the facts. We have the evidence now."

Sarah Munce, a doctoral student in Health Policy Management and Evaluation at University of Toronto, was a Research Assistant on the project. She said that while part of the study confirmed what was known anecdotally, "the study also detailed the complexities of the gaps." Previous reports had profiled acute care to rehabilitation but until the ONF Systems Analysis, not much was known about the continuum of care from rehabilitation into the community.

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How the Study was Conducted

Lead investigator Susan Jaglal, Professor at the University of Toronto and Senior Research Scientist at the Toronto Rehabilitation Institute, specializes in Health Systems Analysis. Under Jaglal's guidance, the study used a variety of approaches including interviews with service providers as well as surveys conducted over the internet.

"We had 100% cooperation," Vander Laan noted. "We conducted 79 interviews with clinicians and for the acute care and children's hospitals, we used an online survey and this is a very handy way to collect data."

The study interviewees were drawn from all sectors across of the province. "The nature of the project really lent itself to a mixed method study. There was a need to ask a lot of open-ended questions," Munce explained.

The Findings

"The biggest finding is not surprising, but now we can speak about it based on the facts. The biggest finding is that we need a huge investment in support in the community. We need to enhance what we're already doing; there

are some incredible programs in the field," Vander Laan said.

Among the areas singled out for immediate attention are mental health services and services for youth and children. "Mental health is a really big problem. We have only five neuropsychiatrists in the province. Clearly we need more. We also need creative ways of simultaneously addressing all the mental health needs of individuals who have a brain injury," Vander Laan said.

The findings in the service gaps for both children and youth as well as for people with mental health issues led to some similar approaches when it came to solutions. The researchers pointed to the need for better collaboration. In the case of children, this means more coordination between children's treatment services, other parts of the ABI system and other service providers for children like the Ministry of Education. In the case of mental health services, investigators identified the need to find a way to treat ABI and mental health or addiction issues simultaneously. Munce said, "The overarching theme is that of breaking down silos, enhancing and

"The biggest finding is that we need a huge investment in support in the community"

increasing collaboration."

Early results of the Systems Analysis were presented at both the Greater Toronto Area Rehabilitation Network and at the International Brain Injury Association Conference in Washington in the spring of 2010. The results will also be published in academic journals in the coming year. In order to capitalize on the findings of the study and to put the recommendations into action, ONF has already issued a call for proposals to address the gaps identified by this study and these proposals are currently under review.

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Work It Out

*Turns out exercise really is good for you...
in more ways than one!*

Life expectancy of people with spinal cord injury (SCI) is approaching that of the non-disabled population. While earlier research for people with SCI was focussed on extension of life expectancy, more recent research tends to address enhancing quality of life and independence for people with SCI.

In keeping with this research trend, the Ontario Neurotrauma Foundation (ONF) funded two studies designed to assess the benefits of an exercise regime in terms of perceived quality of life (PQOL), pain and stress. The first project's objective was to examine the impact of a twice weekly exercise program on a variety of physiological and psychological outcome measures in people with traumatic SCI.

Thirty-four men and women with traumatic SCI ranging in age from 19 to 65 participated in the study. The range of time since injury onset was between one and twenty-four years.

The participants exercised with the benefit of trainers who were able to offer them one-on-one help as needed. The exercise sessions were 90 to 120 minutes

long and included three components:

- warm-ups (wheeling and stretching)
- arm ergometry (15-30 minutes)
- resistance training at 70-80% capacity.

Twenty three subjects successfully finished the nine month study.

Results

The participants reported significantly less pain and stress after the exercise training period of nine months and their perceived quality of life improved considerably. "It was such a positive experience," said David Ditor, study investigator and Assistant Professor in Applied Health Sciences, Physical Education & Kinesiology at Brock University.

In fact the program was so successful that several of the participants wanted to continue exercising after the nine month study was completed. "The MacWheelers exercise program was born," Ditor said. Seven participants who completed the nine month study were invited to continue exercising twice a week. Because the nine month study was over, there was no obligation for the participants to attend the sessions. The researchers wanted to determine if exercise adherence would be maintained even when individuals were under no obligation to attend. "If adherence were not maintained, we wanted to know what would happen to the benefits that were seen in

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quality of life, stress and pain," Ditor said.

Five men and two women who had completed the nine month exercise study were observed for an additional three months. Their exercise attendance was monitored, and following this three month observation, they were retested for quality of life, stress and pain. The three-month follow-up study was also funded by ONF.

"We found that the exercise adherence had reduced by approximately 50% compared to what it was during the initial nine month exercise study, when there was a firm commitment to exercise," Ditor said.

The reduction in exercise

adherence was accompanied by a reduction in quality of life and increases in pain and stress. The benefits that the participants had achieved during the initial nine month study were not maintained once the regime was abandoned, even when some exercise was still being done. "We noticed that pain was a significant predictor of exercise adherence. The worse an individual's chronic pain, the less likely he or she would be to exercise regularly," Ditor said.

Other factors that played a role in the lack of adherence to the exercise included difficulties arranging transportation and secondary health complications.

The two projects have raised awareness in Ontario and even

more generally in Canada that there is a profound lack of accessible exercise facilities. In Ontario, at Brock University in St. Catharines, there is a wheelchair accessible facility and there are facilities at Queens University in Kingston, at Parkwood Hospital in London and at Lyndhurst Centre in Toronto, but beyond the major centres it is not easy to find an accessible exercise facility. And that needs to change because as the two ONF studies prove, exercising regularly is clearly good not only for the body but also for pain management, stress and perceived quality of life.

The results of the two studies were published in professional journals.

Toronto ABI Conference Notes

November 8-9, 2010

In November I was among the almost 528 people that attended the Toronto ABI Conference. I saw a lot of familiar faces, but also a lot of new faces from across the province and the country. ONF was the Partnership Sponsor for this event.

The conference was called "Challenging the Challenges" which was very appropriate considering the presentations that made up the two days. Day One was oriented towards topic-specific presentations, and it was very difficult to decide which sessions to attend as there were so many fascinating presentations. Day Two was a day that I saw as being very valuable to practicing clinicians

in the field of ABI, and the sessions were more like workshops.

ONF research and related projects were well represented at the conference, including a presentation on the Ontario ABI Dataset, School Reintegration For Children And Youth With Acquired Brain Injury, Clinical Guidelines For The Care Of Persisting Symptoms After Mild Traumatic Brain Injury and Can I Return to Work?

If I were to name the theme of the keynote presentations, it would be "don't forget the person behind the brain injury". I found the keynote speeches to be thought provoking, beginning with the address by Dr. Thomas

Kay who spoke about the "self" after brain injury. I was particularly excited by the talk from Dr. Robert L. Karol who spoke about considerations of language use, person-centred approaches and understanding the perspectives of the client in helping people with behaviour issues. Dr. Steve Joordens, a scientist of all people, had the audience listening and laughing as he spoke about "Conscious versus Unconscious Cognitive Processing". Greg Noack finished off the two days with a talk about how he uses his own experience as a brain injury survivor in his work as a rehabilitation therapist. What a great perspective - talk about challenging the challenges!

by Corinne Kagan, ONF Program Director, ABI

Back to School: School Reintegration for Children with ABI in Ontario



Acquired brain injury (ABI) accounts for 30% of paediatric injuries. ABIs are also the leading cause of death and disability in children. While falls are the chief cause of acquired brain injuries, ABIs also result from motor vehicle collisions, sports injuries, abuse, infection, and lack of oxygen to the brain.

A child who sustains a brain injury usually takes a break from regular activities including school attendance. A good recovery for a child with an ABI includes successful reintegration to school.

In 2009, the Ontario Neurotrauma Foundation (ONF) began funding a study to investigate how to improve school reintegration for children who sustain an ABI. The objective of this ongoing study is to collect information about the factors that contribute to success at school for children resuming studies post-injury. The goal is to identify changeable factors so that initiatives to improve school reintegration can target those

factors. As part of the study, the investigators have identified areas that might help predict successful reintegration into school following an ABI.

Currently, 62 children between the ages of six and eighteen years of age are taking part with each participant having sustained an ABI two to five years before joining the study. The children are identified for inclusion in the research by children's treatment centres in five regions of the province. The study team hopes to involve 185 kids.

Predictors of successful reintegration associated with the child include:

- severity of the injury
- age
- pre-injury academic competence
- post-injury neuropsychological competence

Predictors of successful reintegration associated with the educators and school environment include:

- awareness of the programming needs of children with ABI
- instructional approach in the classroom
- attitude towards children with special needs
- aspects of the school environment and procedures in place at the school

Family Predictors include:

- family adjustment to the condition
- socio-economic status

"When we consider the data superficially, we'd expect that severity of injury would predict success of reintegration to some extent. But what we find is that, barring extremely severe injuries, severity of injury is not a very reliable predictor," said lead study

investigator Dawn Good, Associate Professor in the Department of Psychology at Brock University.

"Since injury severity fails to predict a student's success with respect to successes like social, behavioural and academic successes, it may be that more refined tools are needed to measure a child's cognitive and social abilities post-injury," Good said. She hopes that identifying precise measures of a child's skills such as learning, reading non-verbal cues, organizing and planning will improve school reintegration.

Both family predictors are deemed strong predictors of successful school reintegration for children with ABI. The speculation is that people with higher socio-economic status tend to be better advocates for their children, with more tools at their disposal to ensure the child benefits from the best possible services at the school. With greater supports for their children, the family is able to better adjust to the condition.

Advocating on behalf of a child with an ABI is particularly important since ABI is not an identified exceptionality in the school systems in Ontario. Consequently, there is no specific training, limited professional supports for teachers and no system-wide approach geared to help a child return to school after a brain injury.

Good would like to see improvements in teacher skills such as knowledge of strategies, understanding of ABI, and access to supports to make the school environment more accommodating for students returning to classes. A more prepared learning environment, it is hoped, will improve the chances for success for a child with an ABI resuming regular activities and returning to school.

