Social Justice

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The principle of social justice is that all members of society are granted equal rights and responsibilities.

Social justice is a concept whose meaning can be varied, far reaching and, at times, ambiguous, depending on what theoretical, political or philosophical lens one is utilizing.

The United Nations states that social justice is “an underlying principle, promoting gender equality, advocating for the rights of indigenous peoples and migrants, or removing barriers that people face because of gender, age, race, ethnicity, religion, culture or disability.” This indeed is broad and yet all-encompassing and includes disability, but how is it applicable to brain injury?

To put it more succinctly, the principle of social justice is that all members of society are granted equal rights and responsibilities. A health and poverty action organization expands this to include access to quality healthcare. They further purport that access to quality healthcare should never depend on where you live, how much money you have, your race, gender or age, noting that vulnerable and marginalized communities often face substantial barriers.

The world of brain injury is so varied. For some survivors of brain injury who have had access to services with a positive recovery outcome, whether that was through the public health care system or third party funding (e.g. insurance or WSIB) and also a circle of care through friends and family, they would not consider themselves vulnerable or marginalized. For others, they may have indeed faced barriers, including their brain injury not being diagnosed or being misdiagnosed, facing stigma, loss of income, loss of friends and even family, leaving them vulnerable and, at times, marginalized. Where is social justice for them?

I think specifically of our work in North Eastern Ontario. We piloted a program...
to address the need for improved coordination of services for individuals with ABI, including housing and supporting ABI across the continuum, as key to improving the quality of life for individuals with brain injury. Many of the clients we serve fall into the category of vulnerable and marginalized. We have been able to assist with everything from obtaining food (which, according to social justice should be a basic right), to finding housing, mental health services and supports, assisting with return to work and school and being involved with a groundbreaking human rights case. Furthermore, we have supported those who have had issues within our court and criminal justice system.

The criminal justice system is another area where people living with brain injuries are vulnerable and marginalized. A study led by Dr. Angela Colantonio found 43 per cent of prisoners had a history of traumatic brain injuries. In our experience working with those who encounter the justice system, many of their brain injuries were either undiagnosed or they received little to no treatment or rehabilitation.

This past fall OBIA was invited to participate in Corrections Canada Community Health Fairs at four different prisons to promote awareness of acquired brain injury and also the services and supports that we offer. We had the opportunity to speak with inmates and staff. Sadly, many of the inmates we spoke to had similar stories. In essence, they sustained traumatic brain injury, followed by issues with the law or addictions, then incarceration without treatment of their brain injury and, in many cases, chronic pain. Furthermore, they all had very little knowledge about brain injury (which included their own).

If we go back to the principles of social justice that all members of society are granted equal rights and responsibilities, we must conclude that there is still so much work that needs to be done on behalf of those living with brain injuries to ensure that they have social justice.

OBIA has been helping people living with brain injuries for more than 30 years and is intensely passionate and committed to continuing to do so through the lens of social justice.

If you or someone you know is in need of support please call our helpline at 1-800-263-5404.
Beating A Brain Injury

By Matt Gergyek, Carleton Newsroom
Photos by Josh Hotz

On Sept. 6, Etienne Coon-Come Masiringi officially begins his second day as a third-year Social Work student at Carleton University.

A year ago to the date, he was in dramatically different circumstances.

On Sept. 6, 2017 Coon-Come Masiringi was in a hospital bed, preparing to take the final step of a nearly 10-month recovery process from a traumatic brain injury, which meant undergoing reconstructive surgery to have a portion of a 3D-printed skull built into his head.

Accounts of how the injury actually happened on the night of Nov. 27, 2016 are conflicting and difficult to verify, but each begins with the onset of a sudden psychotic episode, induced by a number of stressors, which all hit Coon-Come Masiringi on the same day, including the loss of a job placement and rising rent costs.

The symptom of mental illness affects about three per cent of people in their lifetime, according to the Canadian Mental Health Association (CMHA).

“I get really paranoid, I start hallucinating, I start believing things that are not reality,” he says.

Coon-Come Masiringi quickly called 911 after realizing he was in distress and was transported to the Ottawa Hospital’s Civic Campus via ambulance.

While he was in the waiting room, he became overwhelmed with anxious and paranoid thoughts and fled the hospital to trek five kilometres through the frigid night back to his apartment.

From there, everything goes blank.

Coon-Come Masiringi’s personal theory is that he harmed himself in the midst of his psychotic episode.

Some at the hospital said he fell off a balcony, causing major trauma to his head. Others said it was a physical assault, the fallout of a major blow to the skull.

Either way, Coon-Come Masiringi woke up in the hospital, draped in wires and tubes with a third of his skull missing and his dreadlocks shaved to a stubble, marking the beginning of a tedious recovery process.

“I was angry, I was so confused,” he says.

The injury resulted in major swelling to Coon-Come Masiringi’s brain, forcing surgeons at the hospital to remove a portion of his skull to allow the brain to swell and return to its normal size safely.

To protect his healing brain, Coon-Come Masiringi was outfitted with a bicycle helmet.
WHEN WILL I STOP FEELING SAD?
WHY ARE MY PARENTS SO WORRIED?
WHY DID THIS HAPPEN?
WILL I BE ABLE TO PLAY WITH MY FRIENDS AGAIN?
WILL I BE ABLE TO GO BACK TO SCHOOL?

There is hope for a better tomorrow.

Thomson Rogers is dedicated to getting accident victims the compensation and support they deserve.
Coping with the Brain Injury

But even at the beginning of his recovery, it was clear that Coon-Come Masiringi’s characteristic perseverance and high spirits were unwavering.

If you happened to stay in Coon-Come Masiringi’s ward during his first month at the hospital, chances are you’re quite familiar with his singing voice.

“I would wake up and I would walk the halls . . . singing Christmas songs, whatever song came into my head,” he says.

“It was close to Christmas time so . . . I hope I brightened some of the patients’ spirits.”

Coon-Come Masiringi ended up spending several months at the hospital in various rehabilitation programs, participating in physiotherapy, speech therapy and counselling sessions.

He finally returned home in spring 2017, but that didn’t mean the injury wasn’t still taking a serious physical and psychological toll.

“When you have a piece of your skull missing it’s a constant reminder of what happened,” he says.

Coon-Come Masiringi was plagued by bouts of intense fatigue and intense mood swings.

Leaving the house was especially tough.

“As soon as you enter a store or a public place right away people see the helmet and it’s the only questions they have,” Coon-Come Masiringi says.

He turned to volunteering at the Ottawa Hospital to begin to come to terms with the injury.

“It really helped with my recovery because I knew exactly what the patients [were] going through,” he says. “You’re talking to people, getting to know them. It reminded me a lot of social work.”

When September 2017 came around and Coon-Come Masiringi was finally able to undergo reconstructive surgery, everything fell into place—he was able to go to the gym again and leave the house without being the centre of attention.

“My mood was a lot better, I knew better days were coming,” he says.

Inspiring Others

These days, Coon-Come Masiringi is ready to continue his education to help others. If anything, he says the trauma and difficult times have only made him a stronger and more devoted social worker.

“When you have a brain injury you have no choice; you have to become an advocate . . . it’s your duty,” he says. “I feel like my story has the potential to be a gift for somebody else.”
Specifically, Coon-Come Masiringi hopes to use his Cree background (he comes from Mistissini, Quebec, which means “big rock”) along with his Social Work degree to help Indigenous people throughout Canada who continue to face disproportionate rates of discrimination and unsatisfactory living conditions.

For example, according to the 2016 census, median incomes at four of five Indigenous reserves in Canada fell below the low-income measure of $22,133 for one person.

Meanwhile, while only seven per cent of children in Canada are Indigenous, they make up nearly half of all the entire foster care population in the country, says Statistics Canada.

Coon-Come Masiringi has some important advice on how to work and interact with people with disabilities.

“It’s an invisible disability . . . People with brain injuries don’t have a sign on their head that says: ‘I have a brain injury, be patient with me and don’t put me down.’ Try to be understanding and put yourself in . . . their shoes. Empathize and be compassionate.”

When it comes to coping with mental illness, Coon-Come Masiringi says acceptance and openness is key to recovery.

“You’ve got to get vulnerable and show people you’re not 100 per cent and need help,” he says. He added getting connected with resources and allies is extremely important.

“The worst thing [for] mental health is trying to keep it to yourself and being the only one dealing with it,” he says. “It’s a really big burden to carry [alone].”

To this day, Coon-Come Masiringi is still dealing with some impacts of that fateful November night. His short-term memory, energy levels, processing speed and navigation skills aren’t quite where they used to be, but he’s not giving up on doing what he loves.

“I find when I’m helping people it kind of brings out the best in me,” he says.

Coon-Come Masiringi will work closely with the Paul Menton Centre for Students with Disabilities (PMC) to complete the rest of his degree at Carleton, slowly working his way through his last few credits.

The PMC will provide support for Coon-Come Masiringi, while ensuring he maintains his independence and individuality as a student, by working closely with the faculty members and staff he will encounter.

At Carleton, largely thanks to the PMC, students with disabilities graduate at a rate on par with the general population.

“I want to get back into the things I’m passionate about—social work, helping people, moving my career forward,” he says.

Oh, and he’s working on growing out his trademark dreadlocks.

“They’re growing back, slowly, but surely,” he says with a grin.

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#IAmTheFaceOfBrainInjury

Do you have a story of survival? Do you have coping strategies to share? Are you a caregiver to someone with ABI?

To help spread the awareness of how brain injury impacts our lives, OBIA is pleased to share stories from our readership. The goal is simple:

Share • Inspire • Support

To share your journeys with our readers, email us at: stories@obia.on.ca
Social Justice - It’s the Attitude that Needs to Change

By Brenda Agnew, Client Liaison, Gluckstein Lawyers

At its foundation, the concept of social justice involves making everything equal and levelling the playing field for everyone. It seems like such a simple concept and yet it really is so complex. I don’t think I ever truly understood that more than when I became the mother of a child with a disability.

The reality is that many things in our world are not equal, and even with great advocacy and awareness, the world falls short in providing the same opportunities to everyone. So how do we do better? What are the barriers that prevent this from happening?

In my life as a mother who is raising a child with a brain injury who uses a wheelchair, the most obvious obstacles to social justice that we encounter are the physical ones. The glaring lack of accessibility in areas like transit, buildings, parks. Paying the same price for tickets to a hockey game, but having to sit in an area that is deemed accessible but not able to see past the rail that is right at sightline. Walking into a restaurant where there is no elevator and Maclain has to be lifted up a flight of stairs so he doesn’t have to miss out on a gathering with friends and family. How many times we have heard apologies because we could not get our son into a building, or people blocking our van ramp with illegal parking jobs, so we can’t get into a mall or a movie theatre. Additional barriers are things like lack of closed captioning or real time captioning, appropriate lighting, sound fields, and the list goes on.

These issues can actually be resolved quite easily, but they become a source of great frustration, and they effectively reduce the ability for many people to be an equal participant in society. In most situations it takes multiple attempts to get the message through to the right people, and even then there is no guarantee it will be changed. Removing physical barriers to inclusion and the creation of equitable access, levelling the playing field, are often easy to “fix” and when these barriers come down, opportunities are created quickly. Yet I often find the root of any resistance to address these physical barriers is the attitudes or beliefs of the people needed to make these changes. Theory would dictate that if people truly believed in equality, we wouldn’t have to plead or implore to have things set right, it would just be automatic.

The hardest barriers to social justice that exist in society in my experience are the ones that you cannot see. It sounds cliché, but it is true.

The ones that make the goals of true social justice seem unattainable are those that are attitudinal. The reluctance to make sports programs accessible for all is an example. The automatic assumption that the person with a disability cannot be a valued and contributory member of the team, and cannot succeed in the activity.

My son not being allowed on a skating rink in his wheelchair because of some age-old policy, or poorly trained customer service people who don’t seem to see the issue of not allowing him to be on the rink with everyone else and doesn’t seem to believe that there is a policy that permits him to participate is a typical example. Employers who will not offer jobs to people with disabilities, and in some cases not even
consider them for positions, epitomize the problem. Ignoring their experience, desire and drive to be a tax-paying member of society. By not considering applicants based on their experience, but rather stopping at their disability, their opportunities are limited. How is that social justice? We encourage our teens to get jobs and pay for their own things, we raise our children to learn the value of money and teach them about independence, but then when they hit the “real” world, they come face to face with just how inequitable things can be for people with disabilities who want to get a job.

We encounter educators who jump to modify a student’s curriculum before exploring accommodations that may assist to keep that student at the same academic level as their peers. Instead, assumptions on ability seem to trump common sense and students are placed at a disadvantage before anyone has even had a chance to explore their learning capabilities.

Organizations consciously disregard the needs of people with disabilities because it is too much work, or costs too much money, or the organization is just simply apathetic. People in our world who cannot be bothered or view social justice as a hassle because it goes against the grain of what they have always done, or they just simply don’t understand.

As a community, we have to come together to make the necessary changes so things can be better for everyone. What is good for one is often good for many. When, as an example, an accessible viewing platform is put in at a hockey arena, it is not just for the child with a brain injury who uses a wheelchair. It is for the grandmother who uses a walker and wants to come to watch her granddaughter play ringette. It is for the teenager who broke his ankle and is using a wheelchair and wants to watch his friends play hockey. It is for the new mom with a sleeping baby in a stroller who wants to watch her son learn to skate. It allows everyone to experience the events that are happening.

The best experiences we have had as members of our community, and society...
as a whole, are the ones where people have voluntarily stepped up to open a door, or help us lift our son up some stairs. Strangers who have asked us if they can help, or have just jumped in to improve a situation that would have otherwise left us out. The parents of our son’s peers who find alternate options for birthday parties and play dates because they want him to be a part of it. Future employers who are already making plans to hire him when he is ready and wants to start working. Not because they will receive a government grant for doing so, but because they truly think he would be an asset to their organization. Policies and procedures that include and don’t exclude. Teachers who help students reach for the stars. People who look past the outside and look to the inside to find ways to ensure everyone have the same fair chances in life.

We all have a part to play, that is what social justice is all about. Working as a whole to make things better for the parts, so that everyone is treated equally. By creating equal opportunities for all people, removing those physical and attitudinal barriers that exist around race, disability, religion and so on. We need to look through the lens of many, so we can see what is needed by all.

“Every social justice movement that I know of has come out of people sitting in small groups, telling their life stories, and discovering that other people have shared similar experiences” - Gloria Steinem
Several months after my car accident, I realized the extent of my mild traumatic brain injury when I received a call from Vijaya Kantipuly, group facilitator at OBIA. Her cheerful greeting of our initial meeting was met with my tears.

Following my acquired brain injury (ABI), it was strongly recommended by my physician not to drive in the initial stages of my recovery. I chose to walk as a means of grounding myself and to gain a sense of inclusion.

After several months, I decided to make a date for myself and walk to a local café. It was a mild, sunny morning and I arrived at the café in anticipation of the event. I would be around others and enjoy the atmosphere. The bright blue-eyed server gave me a quick smile and asked if I would be sitting inside. I answered that I wanted to sit outside and enjoy the warmth of the morning.

The question that followed was, “what would you like to have?” I felt my mouth open and was unable to form the words. I was somewhat baffled. I recall the drop of a heavy velvet black curtain hanging inside my head, a barrier that would not allow me to form my response.

My gaze travelled to where the ceramic coffee cups hung from hooks, to where the stainless steel coffee makers lined the wall and I saw there was milk, cream and sugar on the nearby counter. I was looking for anything that would tell me what to say. Even with the surroundings, and even though I knew this was a familiar task, there was no way I could come up with a response. The server took my reluctance as a preference for tea. Unusual for me. On this particular day with coffee permeating the air and all the tools of the trade laid out before me, I was unable to formulate the words needed to order a cup of coffee. To my dismay and being unable to sum up the courage to correct her, I agreed to the purchase of the tea.

As I sat outside facing the sun’s rays, I felt a deep and profound sense of loss and of the things changed by my ABI. Following my walk home, my life raft was the phone call from the friendly voice of Vijaya. We talked of what had happened, and the fear that I was feeling from the experience.

Several more months have since passed. I continue to be challenged daily, sometimes hourly, of issues related to my ABI. However, today, I sit here writing to you my story with a cup of coffee slowly cooling at my side.
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“The problems we face today, can not be solved with the same level of thinking we had when they were created.” A. Einstein

Social Justice and Advocacy

By Al Condeluci, Ph.D.

What is Social Justice?
Social Justice is when people are treated in fair and just ways.

What is advocacy?
Advocacy is about promoting a cause or position on an issue.

What is change?
Change is about creating a new reality.

What is organizing?
Organizing is about mobilizing people toward a common objective.

What is macro change?
Getting the world to change to accommodate the individual. Sound easy? It’s not!

This article is about obtaining social justice by advocating for macro change and orienting yourself or other people toward your cause.

There are many thoughts and perspectives one might take in thinking about social justice, advocacy, change and organizing. Countless books and articles have been written on these subjects. This article, however, takes a broader look at social justice and builds on the key concepts and theories of organizing for both individual, as well as systemic and cultural change. It weaves the key themes that have been associated with successful advocacy, as well as explores times when the change has not been achieved.

In a sense, however, the concept of “macro” change is at the core of obtaining social justice. That is, often when there is a struggle or problem that is at the core of the injustice, often the change agenda starts there. If someone is not doing well in their life, the problem may be with them. And, if they want to do better, they must change. This defines “micro” change and is often the start point for an answer to the problem.

This approach to changing the person, or “micro” change, can be efficacious, and might indeed be the answer to the problem. A simple example here, might be that if a person is not able to communicate in an understandable way, and is having problems, the answer might rest in helping them learn new ways to communicate.

But for some situations, micro change may not lead to social justice, or might even be an unfair burden to the individual. These situations, then, call for another direction – to change
EPS Settlements Group of Canada has launched!

Brad Cantwell, President of EPS Settlements Group, and Bob Nigol are pleased to announce a partnership through the launch of EPS Settlements Group of Canada.

EPS Settlements Group is the flagship company of the oldest and largest structured settlements organization in North America.

Bob Nigol is a former owner and President and CEO of Henderson Structured Settlements and now the Managing Partner of EPS Settlements Group of Canada.

Together Brad and Bob wish to invite past and prospective clientele to engage in what assuredly will be the very highest standard of service achievable in the structured settlements market in Canada.
the culture, environment, or situation around the person to be more accommodating. For when the individual is not the problem (or the problem is misunderstood) we need to take a broader direction. This is when we need to advocate for macro change to achieve greater justice.

It is absolutely essential to understand that advocacy for social justice can happen any time an injustice unfolds. This conflict can be caused by a difference of opinion, the denial of a service or program, or a change in understanding the issues. Needless to say, conflict is the launching pad of advocacy.

Now many conflicts can be resolved through mediation or dialogue. Indeed an entire specialty has been developed in conflict mediation and each year thousands of mediators are trained and dispatched to help resolve disputes. This notion of conflict resolution is important to consider in any dispute because the goal of formal mediation is to have the differing parties come to a mutually amicable solution. In the best of mediation efforts, the disputing parties reach a new solution that is satisfactory to all concerned.

Mediation brings the disputing parties together in an effort to facilitate open communications. The mediator is not a decision-maker or judge, but a conduit for dialogue. They create a safe environment where people can be heard in an unbiased and impartial way. If points need to be clarified or qualified, they help in this process and try to identify new options.

Conflict resolution and mediation attempts to build a peaceful solution and have each party leave the mediation feeling like they can live with the consequences. This is wonderful when it happens, but in some cases of injustice, mediation does not or can not reach this goal. When mediation does not work you will want to turn to an advocacy perspective.

Further up the conflict chain is legal action. This is when the dispute can not be resolved at the mediation level, and the parties advance to a forum where the issue is adjudicated and ruled on by a judge or jury. We are all aware of how this formal legal action unfolds from the many books, movies, and even TV shows that we are exposed to in our culture.

But advocates sometimes need to go further than the rulings of a mediator, or a judge, and to explore the fabric of culture and community, issues that can be at the core of the injustice. This might be the assumptions, perceptions, attitudes, and stereotypes that people may hold that are hard (or even impossible) to legislate or adjudicate.

Advocates sometime must push further when mediation or other peaceful means have failed. We must not only understand the change process, but to work with the concepts and identify the key elements that lead to change. It starts with the delineations between personal, friendship and professional advocacy efforts. In the course of life, most of us will find ourselves in one (if not all) of these places of advocacy. From sending our steak back to be better prepared, to mobilizing fellow congregation members to help put a new roof on the church, to promoting a new law that will make life in our communities better, we are sure to find ourselves in some position of advocacy.

Social justice also require that we look at the dimensions of change. To create a new reality means that we understand the inner workings of the change process. This not only includes how change unfolds, but what leads to resistance to change. This notion of change is an elusive thing. We all know how difficult changing from something we know (even if it is not good) to something we do not know is. History is riddled with example after example of the challenge of change.

Another key variable to social justice is to understand the concept of power. We must be clear that power is the elixir to a changed reality. A range of elements of power will be considered as we look at change. As with change, the notion of power is a difficult concept to get your head around. It seems easy at first – power is the ability to influence. Yet power has been misunderstood. Some have been successful, but for many, power has corrupted.

All of this requires that we manage the basic principles that relate to advocacy. This includes the steps and stages to the advocacy process. Key strategies and tools to change must be employed, yet the challenge really starts with a clear articulation of your goal. In a scientific sense, change is measured when you look at the difference between where you were and where you are now. The distance between these two places is the change. So deciding what you clearly want is critical to the process because it establishes your goal – and gives you a framework to measure your progress.

Often in correcting injustice, the critical ingredient is formal organizing. The more one is organized, the easier the change. This means organizing not only oneself, but to think about how others can be mobilized to your cause. Attorneys promote this in the framework of a “class action suit.” This is when many people are gathered to advocate for the same outcome. This is called “collective advocacy,” when many join the cause for change.
And finally, the core of change is found when your “street smarts” attempt to wrap up the formal and informal efforts you take, on your way to successful change. These street smarts are the simple actions that become important in promoting your cause and correcting the injustice. These include:

**Staying Focused** – Keep good notes, school yourself on the issue.

**Don’t Get Rattled** – Know that injustice brings anger, and anger can cause people to get rattled. Try to keep the issue less emotional.

**Remain Positive** – The social injustice has been negative, but you don’t have to behave this way.

**Bring In New Allies** – Keep people abreast of your issue, and welcome new folks to the fold.

**Keep Moving Forward** – Sometimes justice takes time; don’t give up or settle, if you can help it.

There you have it – an introduction to social injustice and some of the ways and means to move forward. Unfair things happen all the time and most of the time people just give in or acquiesce. However, justice is out there, although it often requires organization and action.

So, let’s get going. Any situation can be changed. It is up to you, however, to stimulate that change. Any one of us can advocate to right a wrong and help create a better world!

“He believes, with all of his heart and soul and strength, that there is such a thing as truth; he has the soul of a martyr with the intellect of an advocate.”

Walter Bagehot

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_Calls typically returned in 1 week and messages will be left if permission indicated._
I look outside each day.
My leg sore.
My heart crushed.
Each day children play.
I yearn to enjoy their merriment.
One day I see a child rolling.
He yearns to build a snowman.
I see his failure to complete.
I want to help but my head says no.
I turned to my solitude knowing I cannot play.

Later I visit my neighbour.
I turned to see a snowman sleeping.
Lying on the snow content in life.
His mother joined saying the snowman fell asleep and needs to be awakened.

We lift the snowman first his torso then his head.
The hat is added with arms raised.
He smiles contentedly with glowing eyes, nose, buttons, and pulsing heart.
A child builds a sleeping snowman for contentment.
I raise the snowman to fulfill his dream.
I realize contentment is just as important as a dream.

By Anthony (Tony) Campesi
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Bayshore HealthCare has been enhancing the quality of life, dignity and independence of Canadians in their homes since 1966. Offering a wide range of personal and community health care services through more than 60 home care offices and 30 community care clinics across Canada, we strive to make a difference in our clients lives – every visit, every time.
I was born and raised in Kamengo, Uganda at the end of an 8-year reign of a brutal tyrant who contributed to social injustices that unfortunately continue to be part of life for the majority of Ugandans today. I spent the first 12 years of my life in rural Uganda with two very strong and no-nonsense, but very loving ladies and I was one of the few fortunate ones to move to Canada, thanks to my mother. My mother Agnes was as tough as they come and if there was a world champion of a hard-working woman, I believe my mother would have won the award numerous times. She left me with my grandmother and aunt like many families do throughout Africa, with a sense of urgency and determination for a better life for herself, but most importantly for me and many others. Currently, I live very comfortably in Ottawa, Canada because of my mother.

My life changed on Dec 19, 2012 when a city garbage truck hit us in Kampala, Uganda. I spent a number of days in a coma only to wake up and be told that my mother was also hit right beside me, and she was dead after seven days of fighting for her life. Today, I consider myself the luckiest man alive. I am truly a walking miracle despite the fact that I have a brain injury that has also drastically changed my life. My mother made me love the village I was born in and her actions over the years made it clear how important it was not to forget where you come from. I am mindful that we are all so very different, but my mother’s actions were and are proof that each one of us, regardless of our economic situation, have the ability to do something small to uplift a few around us that are vulnerable. So, with my shortcomings, one of the projects I wish to carry on with is The Agnes Zabali Boys and Girls Club of Kamengo, Uganda (www.azbgc.ca). This idea came about because The Boys and Girls Club in Ottawa, Canada was instrumental during
Get Connected with Peer Support

“I want to give back and help others who are trying to cope with their brain injury.”

“This program has made me understand I am not alone.”

OBIA’s Provincial Peer Support Program connects persons with lived experience (the Mentor) with an individual who is living with the effects of acquired brain injury and who requires support (the Partner). The program is available, at no cost, to survivors, family members and/or unpaid caregivers.

For more information on Peer Support in your community contact:

Ontario Brain Injury Association
1-800-263-5404  www.obia.ca
my adolescent years. It was so helpful to my mother who had to work multiple jobs and had nowhere to put her children. I thought such a club would help a few vulnerable children in the village who are often starving, angry, afraid and have fewer opportunities in life. I didn’t know how I would start such an initiative but after university, I found myself back in Uganda, completely in love with a country that gave me nightmares, which sadly are still part of my life.

I remain with those nightmares of the village beatings, starvation and death I witnessed as a little boy. The most unfortunate part of all this is that most people in Uganda today remain oppressed and millions are trapped in poverty, while a few live a life of extreme luxuries and are oblivious to the plight of others. I recall the days we were sick and the worrisome look on my grandmother’s face; I recall the days we had no soap or salt nor any income to buy meat or fish. But I must make it clear that despite our daily challenges, my grandmother, aunt and mother were very resourceful women who created a happy childhood life that I would not trade for anything. I only look back now and wonder why I was so happy with the madness all around me. I am who I am today because of the unbreakable foundation that three women with limited resources built in me. That foundation reminds me daily that, regardless of where we live, we all share the same short moment of life and want the same things out of life, mainly shelter, food, health and peace.

There are many cultural events throughout Uganda like a memorial service for a person who passed away. On the day of our accident, we were travelling for my grandmother’s memorial service, which was a very big deal because of who she was and the compassion and understanding she had for others during her life. She fed many and was always available to others in times of need. Unfortunately, we never made it to the village after getting off the plane. I remain with scars, heartache, internal pain and nightmares because of that unfortunate day. Yes, I am very mindful that accidents involving manmade machines like garbage trucks happen throughout the world, but this one didn’t have to happen. I am mindful that people drink and drive with total disregard for others and I am mindful that hospitals and health clinics run out of supplies, but I still believe this accident would not have happened if basic rules of law were followed. The driver of the garbage truck was on the road at 1:00 a.m. and didn’t worry about being stopped by the local police for driving a city garbage truck at night, which was truly not collecting garbage at that time. A garbage truck came out of nowhere and hit my family and the stories from all involved are different. However, this much is clear: that my mother would not have died if this accident had happened in the city that I live in now. One, there are no garbage trucks being driven at 1:00 a.m. because city employees have rules that have to be followed. Two, emergency vehicles would have come and taken my mother to the nearest hospital without worrying about her health card and who would pay her medical bills. The story about this heartbreaking accident is long, but lack of functioning institutions, rule of law, and compassion ended my mother’s
life and I survived due to a miracle. I remain grateful to those that took me to a hospital that was functioning like a modern hospital. It is my belief that the social injustices ended my mother’s life and sometimes it’s hard to think about this, but I remain with enormous strength to carry on with life because of the compassion I have witnessed since the accident.

After burying my mother and recovering enough to fly home to Ottawa, I was admitted to the Ottawa Hospital where I received numerous surgeries and treatment. It was at the Ottawa Hospital Rehabilitation Center that I became aware of my brain injury and it took me a few years to accept my fate. I remain in denial from time to time and try to live life as I did before, but I am reminded quickly by my symptoms, of the reality of my situation.

Remembering my childhood horrors and for years knowing and witnessing unnecessary tragedies, deaths, including children, and the painful challenges of ordinary people obtaining basic health-care services are the reasons I volunteer with the Canada Africa Community Health Alliance (CACHA) (www.cacha.ca) and I have dedicated the remaining years of my life to The Agnes Zabali Boys and Girls Club of Kamengo, Uganda (AZBGC). Despite our limited resources at AZBGC, we have many friends and organizations that have helped us build two outdoor basketball courts and support income-generating projects that have created much needed jobs for youth in the project. Since 2006, the project has become bigger than we imagined and unfortunately after losing my mother and almost my own life in 2012, I have faced some challenges living with a brain injury, but I believe that I was given a second chance to continue my work to give hope where I can and to uplift vulnerable people. I am mindful daily that I am truly a walking miracle and that many people who line up for CACHA’s annual medical missions in rural Africa face much bigger challenges than I do.

In no way am I feeling sorry for myself nor suggesting that I have a difficult life because I have a brain injury. In fact, I don’t share my health issues and too often pretend that all is ok. I am mindful of the painful life and struggles that millions of people in rural Africa face daily. I cannot feel sorry for myself because I live in a G8 country and have access to the best healthcare possible and endless opportunities. Yes, living with a brain injury has absolutely not been an easy thing for me because it is an unseen injury by others. In my own view, I was a very strong man before the accident and unfortunately the world moves too fast for most of us to stop and ask how one is feeling and truly listen. No one has that time and it is my view that it is worse for a person with a brain injury. On the outside, I am as healthy as one can be. I have a tendency to be competitive, which leads me to do things that I ought not to do, but I do it so that I am not judged by others. I also believe a man shouldn’t live his life worrying about being judged but I sometimes do, and I shouldn’t. I shouldn’t because I have other things in my head to deal with and I am mindful of the tremendous services available to me by the outstanding healthcare workers that continue to support me. I agreed to share my story in hopes that it can inspire someone else dealing with a brain injury to find a passion in volunteering. It is my belief that such passion will give a more meaningful purpose to their life in the midst of pain. To my shock, I have learned that there are many victims of brain injury, which reminds me that I’m not alone in taking on the challenges from brain injury. Helping others even across the sea has made a positive difference to me because without this passion, I imagine the brain injury dominating my life and winning and this can not happen.
The sheer prevalence of brain injury among those incarcerated is striking, with estimates up to 10 times greater than the general population and rates between 20 and 90%\(^1\). A Canadian study found that the risk of incarceration among young adult males and females with traumatic brain injury (TBI) was 2.5 times greater than their counterparts without TBI.

Women are more likely than men to experience a TBI before any involvement with the criminal justice system\(^2,3\). They are also more likely to report being victims of childhood abuse\(^2\). They face a higher chance of being convicted of a violent than non-violent crime\(^4\). One of the leading causes of TBI among women who come into contact with the criminal justice system is violence, often intimate partner violence\(^3\) (Durand, 2016; Jackson 2002).

The symptoms associated with TBI may affect a person during their incarceration in a variety of ways. These include memory deficits, attention problems, anger and/or slow verbal or physical responses. Correctional staff may misinterpret these behaviours and take disciplinary action when instead identification and treatment of the injury would be the prudent course of action. Currently, no screening programs are used to identify TBI in our correctional system. An understanding of early life experiences, medical history, and the injury event is important information to assess the best treatment for people having difficulty adapting to the prison environment because of a brain injury\(^2\).

TBI can be a barrier to participating in programs aimed to reduce recidivism (e.g., substance abuse treatment) and translate to renewed unhealthy consumption patterns after release, which, in some circumstances, may cause death from overdose\(^5\). Inability to adhere to conditions of release, often abstinence from alcohol and drug use, jeopardizes a person’s ability to remain prison-free. As such, it becomes extremely difficult to break the cycle of reincarceration.

Social determinants of health and incarceration

Experiences of early childhood abuse and neglect, poor educational attainment, racial and ethnic disparities, sex/gender inequities, poverty and homelessness are abundant among people experiencing incarceration. People in the correctional system experience mental illnesses and addictions, chronic illnesses (e.g., HIV/AIDS) that are co-morbid with traumatic brain injury; thus the burden of illness is greater as are barriers to their care. They experience difficulty accessing social and health services for a myriad of reasons such as discrimination, long wait lists, no fixed address, and financial insecurity.
If you are receiving a settlement for a personal injury claim, you need to consider a structured settlement - the only no fee, tax-free investment option available that ensures long term stability for the injured party.

For a no-obligation consultation, we invite you to contact our office today.
There is a high prevalence of homelessness among people who are released from prison. One study reported that roughly one in five prisoners in provincial custody in the Greater Toronto Area reported being homeless at the time of admission\(^6\). Once released from the prison system, it is often difficult for them to get stable employment because of their criminal record, which can perpetuate the cycle of poverty, homelessness, hastened return to custody. These experiences can be incredibly stigmatizing and can erode family and community ties.

**A hidden health issue in our prisons**

TBI is a serious and hidden health issue in the correctional population that is compounded by additional health concerns such as mental illness, substance addiction, and post-traumatic stress disorder. There is no mechanism for identification of TBI or its severity upon entry into Ontario correctional institutions. This is a serious matter given that behaviours and emotions associated with TBI may be misinterpreted by law enforcement officials and by correctional staff, before and during incarceration. Within the correctional institution, people with TBI may find themselves in violation of rules which, if sufficiently severe, can result in prison misconduct charges.

A history of TBI among those incarcerated is associated with impairments such as verbal memory, learning, and abstract thinking, that together lead to problems with general memory and socialization, and consequently, with prison adjustment and program completion (e.g., institutional charges, failure to complete substance abuse programs\(^7\)). These difficulties may affect functioning both inside and following release\(^8,9\). Many incarcerated individuals live with TBI-related health and social problems that complicate their diagnosis, management, and treatment for substance use\(^5\). Most people who are incarcerated will be released so these problems will continue to pose challenges for them at re-entry to the community and can lead to re-incarceration.

The coexistence of substance abuse and TBI has also been well documented in the correctional setting\(^10,12\). TBI, even mild TBI, can result in problematic post-concussive symptoms, including irritability and headaches\(^8,9,13\) disruptions in general memory and socialization. These difficulties may affect functioning both in correctional settings and following release\(^8,9\). Many incarcerated individuals live with TBI-related health and social problems that complicate their diagnosis, management, and treatment for substance use\(^5\). The majority of persons with a TBI do not seek medical care. A recent study in Ontario found that women who had been criminalized preferred not to seek medical treatment for head injury because of negative experiences with health professionals who were judgemental of their lifestyle\(^14\).

**References**


Thank you to our Corporate Champions

For more information on how to become a Corporate Champion, visit:

www.obia.ca
CALL FOR ABSTRACTS

The Ontario Brain Injury Association (OBIA) in collaboration with participating Community Associations, is pleased to announce that the Provincial ABI Conference 2019 will be held on November 6-8, 2019 in Niagara Falls.

The theme is:
Forging New Pathways • Navigating Challenges • Exploring Breakthroughs

The Provincial Conference Committee is seeking oral presentations from professionals, researchers, survivors and caregivers that will reflect our theme.

In particular, we are seeking submissions that describe research initiatives, technologies, breakthroughs, delivery models, novel therapies or interdisciplinary advances that have the potential to set the stage for forging new pathways, navigating challenges or exploring breakthroughs. We encourage collaborative presentations that demonstrate links between clinical practice and the experiences of survivors and caregivers.

All abstracts will be reviewed by the Abstract Selection Committee for relevance, quality of content, originality and province-wide representation.
OBIA Advisory Council (OAC) Report

The OBIA Advisory council met on November 10, 2018 at the Miles Nadal Jewish Community Centre. There were 21 people in attendance representing 12 associations, and four attending by webinar.

There was no formal workshop, however, plans for this year’s Brain Injury Awareness Month were discussed.

Due to inclement weather, the January OAC meeting had to be cancelled.

Archived videos of past workshops can be found on OBIA’s Vimeo page: https://vimeo.com/obia.

The following reports are from some of the local community associations:

BIA Windsor Essex

Capping off the Brain Injury Association of Windsor and Essex County’s events of 2018 was the December social. Comradery and fellowship was the theme of this year’s Christmas event. Everyone had a good time enjoying a turkey dinner complete with pumpkin and apple pie.

More than 25 people turned out for this event and social group coordinators Alesia and Christina made sure everyone was involved in the games—complete with prizes for the winners. The most fun prize was a present wrapped with 23 layers of paper—each carefully unwrapped by all. Donna unwrapped the last layer and claimed the prize of a large ball of chocolate.

Each person left with a smile, a full stomach, and memories of an evening of fun and laughter with a gift to take home.

Brain Injury Society of Toronto

It has been a very exciting time at BIST as we were thrilled to participate in the Persons with Disabilities Community Consultative Committee, Town Hall meeting, in November with Police Chief Saunders and other members of the police force. Attendees of the Town Hall meeting got to see the first screening of a police training video. The video is a tool for the members of the police force to work with people with hidden disabilities like brain injury. BIST looks forward to continuing its advocacy efforts with the committee to foster
positive relationships with the police force and those with brain injuries. We are excited to announce that we will be able to share this video with our community soon! Follow us on social media or check our website regularly for the link when it's released.

We would also like to thank everyone for supporting and making donations to our BIST Wall of Heroes this year on Giving Tuesday. BIST hosted an open house to its members and neighbours in the community to raise awareness about brain injury and the services available while enjoying each other's company and having a warm drink and treat!

BIST also hosted an ABI and Sexuality workshop led by Reema Farhat from West Park, which discussed how to develop healthy sexual practice following an ABI. The workshop presented a safe space for those of all genders and sexualities living with a brain injury to discuss best practices when it comes to having safe and healthy sex after an acquired brain injury. The workshop was also followed by a question and answer period for members.

BIST’s 2018 Holiday Party was the place to be during the holiday season. This year we had a record turnout of members, volunteers and representation from the offices of MP Jill Andrews and MPP Carolyn Bennett. The holidays were celebrated with lots of food, trivia, and amazing company. The party featured the greatest photo booth ever, made by our wonderful special events committee and you could feel the holiday cheer from a mile away. A special thank-you to all our members and volunteers who made the holiday party such a success!

BIST has been busy working on 2019 programming and is excited to announce its new Men’s Social Drop-In as well as a Post-Concussion Syndrome Peer Drop-In. We are also looking forward to our upcoming Paint Nite Fundraiser on March 7. Stay tuned for more exciting news from BIST!

BIA Peel-Halton

We are excited about our conference because its focus is education from health advocates, not just lawyers and law clerks, but members of many health-care practitioner groups (OTs, SLPs, RTs, CMs). We have also invited insurers to sit on a panel for a question and answer period. We hope to see you and some of your team attend the conference. Registration
details can be found on our website (www.biaph.com).

We hope that you will be able to support BIAPH by becoming a sponsor. Please visit our website (www.biaph.com) and click on the link, which will take you to our Sponsorship Matrix.

As part of Brain Injury Awareness Month, we have a dedicated space where we are featuring an “Unmasking Brain Injury” display, which is being sponsored by the Canadian Medical Assessment Centre.

**Hamilton Brain Injury Association**

**Bikes, Blades & Boards Report:** HBIA’s volunteer-run injury prevention program was delivered to 1,162 students within Hamilton, Haldimand-Norfolk and Niagara in 2018. This year, we anticipate to deliver our new curriculum to more than 1,500 students. Thank you to our committee, community partners, volunteers and sponsors for your dedication to the program. If you would like to get involved with Bikes, Blades & Boards, visit our website at www.hbia.ca and click on the Education tab to complete a program application or volunteer application.

**Seizure & Brain Injury Centre - Timmins**

The Seizure & Brain Injury Centre has had a very busy past few months. We have introduced a Youth Group and a Women’s Social evening along with our other regular programming.

Despite the cold weather, more than a dozen clients attended our afternoon Christmas party. They enjoyed a great meal of homemade beans, potatoes, ham and desserts all prepared by our multi-talented staff, Samantha Saley and Rebecca Harvey.

Tickets have gone on sale for our Annual Spring into Summer Draw to be held on Mother’s Day, May 12, 2019. Proceeds from the draw go towards our New Beginnings day programming. We continue to have great support from the community. A big thank-you to the businesses that contributed to the draw: Cy Rheault Construction, Dabrowski Meats, Timmins Home Building, Cedar Meadows Resort & Spa, Cousineau Fine Jewelry and JT Couple Dancing.

HBIA has teamed up with OBIA to bring the Peer Support Program to Hamilton. We are currently looking for survivors, family members and unpaid caregivers to join our growing Peer Support Program.

Mentor/Partner matches are time specific and are made province-wide based on similar experiences, needs and personal interests. Mentors and Partners talk primarily by phone so participation from home is optimal. To refer a client or get involved, please contact our office.

In addition, we are currently looking to add to our Board of Directors. If you are interested in applying for a board position, please contact us.
We are gearing up for another Brain Basics to be held May 2 - 3, 2019. This program is always well-received and much needed in our community.

The Seizure & Brain Injury Centre recently started a Women’s Social Evening once a month. One of the participants shared her skills in making Dream Catchers.

**BIA Sudbury & District**

We have released the next Singing and Ka-ching-ing video to raise money for the Brain Injury Association Sudbury and District! For every share we will donate $1 to BIASD up to $400.00.

**Home Instead Senior Care - Singing and Ka-ching-ing for BIASD’s Golf Tournament**

On November 27, 2018, BIASD was fortunate to be a recipient of a grant from the Sudbury Community Foundation through the Gord and Pat Slade Heritage Fund in the amount of $1,000 for the Unmasking Brain Injury Program. Fred Slade, son of Gord and Pat Slade, and Brandon Beeson, Vice-President of the Sudbury Community Foundation, presented a cheque to Julie Wilson, Director.

On Thursday, December 6, 2018, Brain Injury Association Sudbury & District in collaboration with March of Dimes Canada hosted our Annual Holiday Gala: A Sparkling Night. With more than 120 people in attendance, the gala was an amazing success, bringing together community members for a night of dinner, dancing, and holiday spirit!

**BIA Quinte District**

**The Art of Healing**

BIAQD was honoured to receive a grant from the City of Belleville Community Arts and Culture to run a 12-week art program focusing on the positive aspects that it has on ABI recovery.

Our program teamed up with local artists to bring a variety of new art techniques, and various forms of art to help them expand their skills. They enjoyed getting their hands dirty while making wonderful works of art during the pottery sessions, as well as creating beautiful quilts, and amazing paintings from different mediums.

Their hard work didn’t go unnoticed. BIAQD was able to host an Art Show at the Core Gallery during the week prior to finishing the project. The community turnout was amazing, and some of the participants were able to sell their art pieces.

We are looking forward to the many things we have planned for the New Year. We will be hosting our 2nd Comedy Night on May 2, 2019. The evening will feature a Yuck Yuck’s comedian, and tickets are $25. It is sure to be a great evening. We are also going to be holding a craft-vendor-bake sale in May. There will be many local vendors selling their amazing products, as well as our own BIAQD artists selling their crafts and goodies. All proceeds from this event will go to support our 12 weekly programs that are offered at our Association.

Be sure to check out our new website ([www.biaqd.ca](http://www.biaqd.ca)) to get information about upcoming events, programs, and all the wonderful things that we do! ☞
“McKellar provided peace of mind for the rest of my life.”

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Each year, a number of Ontarians suffers catastrophic personal injuries as the result of auto accidents, medical errors, and historic sexual abuse. As many OBIA members know, settlements or awards received in respect of these catastrophic injuries are essential life supports for injured people.

After suffering a catastrophic injury, injured people are faced with a complex series of legal and financial decisions they will have to make—decisions that will have a serious and lasting impact on their and their family’s future health and financial well-being.

One key decision involves whether an individual advancing a claim for personal injury should take the eventual settlement or award entirely as a lump sum or in part as a lump sum and part as a structured settlement. A lump sum is a single, one-time payment, while a structured settlement means that the portion of the settlement that is structured is paid periodically.

Structured settlements provide an individual who has suffered a personal injury with a guaranteed, virtually risk-free, ongoing source of funds to meet their future care and medical needs. Structure payments are tax-free, are not reported on tax returns, and can help an individual preserve means-tested government benefits they currently receive or may become eligible for—benefits which may be lost or forfeited if that injured person receives a lump sum settlement.

Unfortunately, rules and regulations in place regarding social assistance eligibility have created confusion around structured settlements for injured people who need social assistance. For example, Ontario Disability Support Program (ODSP) provides support to individuals who require assistance with necessities like food, shelter, medication, and basic living needs. In contrast, a personal injury settlement is compensation specifically for damages incurred by an individual as a result of their injury, such as medical expenses, care needs, assistive devices, and much more. Obviously, ODSP recipients who have suffered a personal injury need both sets of support—both medical, for their injury, and living support, to meet their basic needs.

At present, the government of Ontario supports an ODSP eligibility regime that effectively penalizes structured settlement recipients; that is, personal injury settlement funds which are specifically exempt from consideration for eligibility by ODSP may eventually lose their exempt quality when placed in a structured settlement. At present, an injured person cannot receive both unaffected ODSP benefits and a structured settlement. No such penalty exists for an injured person who receives a lump sum of their personal injury settlement.

Crestview Strategy is working on behalf of a structured settlement company to advocate to the Ontario government to ask them to ensure consistency of regulations and rules for social assistance recipients who receive structured settlements as part of the resolution of their personal injury claims.

The Government of Ontario and specifically Lisa MacLeod, the Minister of Children, Community and Social Services, have indicated a commitment to facilitating access to social assistance for vulnerable Ontarians, like catastrophically injured people, and are in the process of modifying Ontario’s social assistance framework. We are eager to continue working with the government to see them discontinue rules that serve as a disincentive or penalty for structured settlement recipients who also need social assistance.
The awareness of traumatic brain injury (TBI), but primarily concussion, has never been greater among the general public. This is in part due to the incredible growing knowledge around the short- and long-term consequences of concussion, particularly in professional sports.

Historically, TBI was more common among men, with research samples tending to be mostly characterized by males. The reality is that research conducted on predominantly or exclusively male samples is not necessarily generalizable to females. In the basic sciences, until very recently, it was common practice to do research on exclusively male rodents. The findings of these studies formed the basis for clinical research such as clinical trials. However, researchers that used both sexes in experiments made important discoveries, which showed different pain receptors and brain structure by sex as well as differential recovery patterns after a TBI.1,2,3,4

With respect to concussion, while evidence is mixed, females have been found to have higher incidences of concussion in sports with similar rules.5 Further, they have been found, on average, to have longer recovery time.4,6 Clearly, this needs further study and, as such, research that integrates explicit consideration to sex and gender is needed to understand these trends.

In a recently published paper in the Journal of Women’s Health, our lab found that during a 10-year period in Ontario, there was a greater than 80% increase in the number of concussions reported from emergency departments across the province among females versus a 19% increase among males. This rise in the number of female concussions clearly shows a need to address female brain injury specifically. In our study of 90,000 emergency room visits, we found that females were significantly more likely to have an injury to the neck as a co-existing diagnosis with concussion. Having less neck strength, interestingly, has been proposed as one of the reasons why women may be more susceptible to concussion than males.7,8

The study mentioned above all highlights the importance of having sex-specific data that considers the female body. For instance, in looking at menstrual and hormonal changes our lab has documented menstrual cycle disruption that occurs after a moderate to severe brain injury and can also occur after a minor brain injury such as a concussion.9,10 Previous research has also found that concussion outcomes may vary depending on the menstrual phase of females at time of injury.10 In conducted focus groups, women indicated a keen interest in having access to such information.11 Our lab also focuses on brain injury in circumstances that differentially affect women such as in the context of intimate partner violence (IPV).11,12 IPV affects approximately one out of four women in Canada and up to 92% of the violence is inflicted on the head, which increases chances of a brain injury. Studies that have examined TBI in this context have documented that most of the injuries are unreported.

I wish to applaud the advocacy of the Ontario Brain Injury Association to raise awareness on this issue through special lectures and public education campaigns. A few years ago our lab held what we believe to be the first national workshop bringing the world of brain injury and IPV together. This was attended by researchers, clinicians, advocates, service providers and persons with lived experience. At the conference, we reported on a survey that indicated a very high need for education among agencies providing front-line care. This event has been captured in a video on our lab website www.abiresearch.utoronto.ca. In response, we have developed a toolkit that provides a resource for front-line
providers that is currently being tested in Victoria, B.C. in collaboration with the Cridge Centre and the Greater Toronto Area. 13

The good news is that international funding agencies have funding policies in place that require investigators to give explicit consideration to sex and gender in their research proposals. The Canadian Institutes for health research (CIHR) is considered a world leader in this area and even has a separate Institute for Gender and Health. Last year I was invited to be part of a conference at Health Canada. In his opening address, the Federal Deputy Minister of Health stated that we need better understanding of female concussion! The Status of Women Canada recently released a video on concussion that in fact addresses sex and gender analyses. This form of analysis considers factors associated with sex (biological), gender (norms, identities, expression) as well as intersecting factors such as ethnicity and socioeconomic status.14 Overall, research that explicitly considers sex and gender is being recognized as highly valuable to feed into guidelines in order for them to be gender responsive, which has been historically lacking in research.

Our lab at the University of Toronto and the Toronto Rehabilitation Institute has been leading a significant program of research that addresses sex and gender specifically. Our analyses on large population data sets have found different comorbidities for men and women in inpatient rehabilitation settings. For example, we have found that for older adults with a TBI diagnosis, women are more likely to have musculoskeletal conditions than men. The more common comorbidity for both sexes was circulatory conditions. 15 Further, we have integrated sex and gender in our work on marginalized populations. 16 Another project we are working on investigates whether having explicit consideration to sex and gender in knowledge transfer such as through patient education materials has any influence on outcomes. It is important to note that research that integrates sex and gender considerations informs better science for not only women but also men and gender diverse individuals.

What is most rewarding in this work is the expressed need for this kind of research from the end users of the information. I co-lead an international task force on Girls and Women with Acquired Brain Injury through the American Congress of Rehabilitation Medicine. 17 The task is comprised of researchers, clinicians, advocates, and persons with lived experience. We have representation from leading advocates such as the Disabled Women’s Advisory Network, the Brain Injury Association of America and Pink Concussions, a non-profit dedicated to education and awareness of female brain injury. One of the projects of the task force has been an entire special issue in the Archives of Physical Medicine and Rehabilitation in 2016 entitled “Sex, Gender and Traumatic Brain Injury,” which is a freely available. 18 I draw much inspiration from this group and from all the countless supporters of our research program.

References

I really don’t know who I’m supposed to be. I was born Kyle Weaver but at age five and in the space of a few seconds I became somebody else bearing the same name. I was young enough when it happened that I really don’t remember my previous self. For the record, my story has been recorded here primarily by my father. It is a composite of my life as seen through my eyes and based on incidents as described by my parents.

I was born in 1979 and I’ve been told repeatedly that I was a difficult child from birth. Many years later I was diagnosed with Autism Spectrum Disorder previously labelled Asperger’s. Apparently, this explains a lot of the odd behaviour that I exhibited all through school and continue to do today. As you may note, this story is full of labels, most of which are not complimentary.

When I was five years old, the doctors decided it would be a good idea if I had my adenoids removed to improve my breathing. I was called a “mouth breather” because I breathed almost exclusively through my mouth, even when I was asleep. The adenoidectomy did not go as planned because I had an adverse reaction to the pre-op medication and went into cardiac arrhythmia or possibly complete arrest and nearly died. The hospital staff told us very little but we do know that the crash cart was brought in. It was serious enough that I suffered cerebral hypoxia causing permanent damage to my brain. Since this took place in the 1980s there was little or no protocol in place for potential brain injury so I was released to my parents’ care with the hospital staff being pleased that they had not killed me. The real irony of this whole scenario is that the surgery never helped my breathing as I’m still a “mouth breather” today, just a different one that entered the hospital. The seriousness of this did not really come to light until many years later as I will continue to explain.

As if having Asperger’s didn’t cause enough chaos in my life, this disability had now been amplified severalfold because of the re-wiring of my brain. Brain injury has been labelled the invisible disability making it difficult for people to understand my odd, unusual and even weird behaviour, which continued...
and actually got worse. My parents say that I came out of the hospital that day a different person. I was no longer that happy-go-lucky little boy they had been raising; rather, I had become very moody, disagreeable and even angry most of the time.

In school, I became an easy target for the bullies. I was constantly tormented, picked on and outright embarrassed which did little for my self-esteem or my mood. I would act out in class but I really don’t know why. I was doing what felt right at the time. My parents paid the price as they were regularly being invited to the school for meetings and being blamed for my behaviour. After all, good behaviour starts at home but the school assumes no responsibility for a child’s behaviour. The school system was not interested in digging any deeper to try to discover a root cause. That’s just not on the curriculum and they were more focused on the fact that I did not fit the pre-established mould. I had to repeat grade two but most of the teachers were happy to adjust my grades a bit and pass me up the ladder for someone else to deal with. I was tested for learning disabilities at one time but, of all the recommendations made, the only ones that were followed up involved speech therapy. A simple bandage but hardly a solution.

During one of the latter years in public school, a never-identified assailant hit me from behind with a chunk of ice. I was knocked out completely and bleeding profusely. I was taken into the school where they cleaned up most of the blood and I was allowed to have a nap which, understand, is the antithesis of what should have taken place. Later, I even returned to class. Schools at that time had no concussion protocol and at the end of the school day, I was sent home with no concussion protocol and at the end of the school day, I was sent home with.

At the hospital that day a different person. I was no longer that happy-go-lucky little boy they had been raising; rather, I had become very moody, disagreeable and even angry most of the time. My parents paid the price as they were regularly being invited to the school for meetings and being blamed for my behaviour. After all, good behaviour starts at home but the school assumes no responsibility for a child’s behaviour. The school system was not interested in digging any deeper to try to discover a root cause. That’s just not on the curriculum and they were more focused on the fact that I did not fit the pre-established mould. I had to repeat grade two but most of the teachers were happy to adjust my grades a bit and pass me up the ladder for someone else to deal with. I was tested for learning disabilities at one time but, of all the recommendations made, the only ones that were followed up involved speech therapy. A simple bandage but hardly a solution.

Life in school continued the same through public school, junior high school and into high school where I hit another wall. My grade nine homeroom teacher had a very narrow field of tolerance with regard to acceptable behaviour and performance. My parents had many meetings with her and before the year was over, we were given the choice of either having me repeat grade nine or being relocated to another school. This other school was Kernahan Park Secondary School and it specialized in caring for students with both learning and behavioural disabilities. At this school, I excelled because the teachers were not only understanding and creative, but they were also flexible in their curriculum and approach. I won several awards and certificates of accomplishment plus opportunities to train in a variety of interesting trades such as culinary arts. Unfortunately, shortly after I graduated, Kernahan Park closed due to funding cuts, so there is no longer a safe haven like it remaining where the unwanted can be treated with dignity.

While I was at Kernahan Park, our family experienced another paradigm shift. My mother was hit by a car while riding her bicycle and what happened to her is important to what happened next in my life. She was knocked unconscious and most of her injuries were to her face and head. When my dad caught up with her at the hospital, she couldn’t remember her address, phone number or many other important bits of information, yet the hospital released her without further examination, telling her how lucky she was having no broken bones. She wasn’t lucky at all for she had sustained a traumatic brain injury. About nine months after her accident, my mother was put in touch with Brain Injury Association of Niagara (BIAN). Both my mother and my father diligently started attending peer support group meetings and it was because of the invaluable information gained that a light came on regarding their son, me. They took a critical look back at what had transpired in my past and soon recognized many common symptoms of an ABI, and quickly answers to many haunting questions of my past became clear to them. They joined the dots and realized what had ultimately happened that day when a simple surgery went all wrong. Both my mother and I were robbed of that golden period of time following an acquired brain injury when cognitive training could potentially make the biggest difference to a person’s recovery.

It wasn’t long until I was accepted as a member of BIAN with a dual membership in OBIA and I was able to take advantage of a partnership with the Walker Family YMCA. Around that time, I also discovered Special Olympics Ontario (SOO) and started participating first in power lifting but soon discovered some of the other sports programs such as baseball and swimming. This meshed perfectly with my YMCA membership as I could strength train in the gym and work on my swimming in the pool. This additional training helped me compete effectively in the various Special Olympic sports and I experienced several successful seasons in:

- Soccer - I competed in the Provincial Games and our team qualified for the National Games;
- Bowling - I set the highest single game score ever at 256;
- Power Lifting - I competed in the Provincial Games and won both gold and silver;
- Baseball - I competed in the Provincial Games.

Eventually, I retired from most of the other sports and focused all of my efforts on swimming. I became a breaststroke specialist and I regularly compete in the 25-, 50-, 100- and 200-metre events and recently expanded to the 400-metre. In 2017, I swam in the SOO Provincial Games and came home with four gold medals. That performance was sufficient to qualify for the Special Olympics Canada National Games in Antigonish, Nova Scotia. This was the thrill of a lifetime with the games taking place from July 29 to August 5, 2018. I was able to experience...
some of that great East Coast hospitality while meeting athletes from all provinces and the territories. All that hard work at the YMCA paid off as I returned home with one gold and one silver medal swimming at the national level.

In retrospect, I owe a debt of gratitude to the BIAN and OBIA organizations, and especially Pat Dracup, the program Director at BIAN, for their support and access to the YMCA program. The BIAN agreement with the Walker Family YMCA allowed me to squeeze in all the strength training and additional pool time necessary to be successful in Nova Scotia. This isn’t the end of the story as I’ve started training again to compete in the Ontario Provincial qualifier which takes place in the spring of 2019. I’ve been told that my performance in Antigonish only just missed out on qualifying me for the World Games in Abu Dhabi, 2019 by a very small margin. I believe that with continued hard work and focused training at both the YMCA and the Kiwanis Aquatic Centre, I’ll qualify again for the Provincial Games, then the Nationals and who knows, perhaps this time, the World Games in 2023. I understand they may be held in Berlin, Germany.

Wish me luck!

A special note, my Mother, Kerry Weaver’s inspirational story and many others like hers can be read in the BIAN publication “Winds of Change” available through the BIAN office.
Events Calendar

March 13-16, 2019
International Brain Injury Association presents: *The 13th World Congress on Brain Injury*
Location: Sheraton Centre Hotel, Toronto, ON
Contact: IBIA Secretariat
Phone: 713-526-6900
Email: congress@internationalbrain.org
Website: www.ibia2019.org

March 17, 2019
OBIA, Brain Injury Canada & Brain Injury Society of Toronto host: *Special Workshop Event for Survivors and Caregivers*
Location: Sheraton Centre Hotel, Toronto, ON
Contact: Terry Bartol
Phone: 905-641-8877 ext. 234
Email: tbartol@obia.on.ca

April 29 - May 2, 2019
OBIA Training Program
*Neurorehabilitation: Assisting Recovery & Function in Everyday Life Following Brain Injury (Level 1)*
Location: Dalhousie University, Halifax, NS
Contact: Diane Dakiv
Phone: 905-641-8877 ext. 231
Email: training@obia.on.ca
Website: www.obia.ca

May 2-3, 2019
Hamilton Health Sciences presents
*26th Annual Conference on Neurobehavioural Rehabilitation in Acquired Brain Injury - Brain Injury Rehabilitation: Mental Health and Addictions*
Location: Hamilton Convention Centre, Hamilton, ON
Contact: John Zsofcsin
Phone: 905-521-2100 ext. 40868
Website: www.hamiltonhealthsciences.ca

June 12, 2019
*BIST/OBIA Mix and Mingle*
Location: TBA, Toronto, ON
Contact: Terry Bartol
Phone: 905-641-8877 ext. 234
Email: tbartol@obia.on.ca
Website: www.obia.ca

June 19-21, 2019
OBIA Training Program
*Advanced Brain Injury Rehabilitation (Level 2)*
Location: Brock University, St. Catharines, ON
Contact: Diane Dakiv
Phone: 905-641-8877 ext. 231
Email: training@obia.on.ca
Website: www.obia.ca

November 6-8, 2019
Location: Sheraton on the Falls Hotel, Niagara Falls, ON
Contact: Terry Bartol
Phone: 905-641-8877 ext. 234
Email: conference@obia.on.ca
Website: www.ontarioabiconference.ca

For more listings, check: www.obia.ca/events
Brain Injury Associations

Ontario Brain Injury Association
Phone: 905-641-8877 or 1-855-642-8877
Toll-free support line 1-800-263-5404
Email: obia@obia.on.ca  Website: www.obia.ca
- www.facebook.com/OntarioBIA
- www.twitter.com/OntarioBIA
- www.instagram.com/OntarioBIA
- www.LinkedIn.com/company/Ontario_Brain_Injury_Association

Belleville
BIA of Quinte District
Phone: 613-967-2756 or Toll free: 1-866-894-8884
Email: info@biaqd.ca
Website: www.biaqd.ca

Chatham-Kent
New Beginnings ABI & Stroke Recovery Association
Phone: 519-351-0297
Fax: 519-351-7600
Email: info@newbeginnings-cksl.com
Website: www.newbeginnings-cksl.com

Dufferin County
Headwaters ABI Group (HABI)
Phone: 519-215-1519

Durham
BIA of Durham
Phone: 905-723-2732 or toll free: 1-866-354-4464
Email: information@biad.ca
Website: www.biad.ca

Fort Erie
BIA of Fort Erie
Phone: 905-871-7789
Email: biafeoffice@gmail.com
Website: http://braininjuryfe.wixsite.com/biafe

Hamilton-Wentworth
Hamilton BIA
Phone: 905-538-5251
Email: info@hbia.ca
Website: www.hbia.ca

London and Region
BIA of London and Region
Phone: 519-642-4539
Email: info@braininjurylondon.on.ca
Website: www.braininjurylondon.on.ca

Niagara Area
BIA of Niagara
Phone: 905-984-5058
Email: pat@bianiagara.org
Website: www.bianiagara.org

North Bay Area
BIA of North Bay and Area
Phone: 705-478-8664
Email: contact@bianba.ca
Website: www.bianba.ca

Ottawa Area
BIA of Ottawa Valley
Phone: 613-233-8303
Email: contact@biaov.org
Website: www.biaov.org

Peel-Halton
BIA of Peel & Halton
Phone: 905-823-2221 or 1-800-565-8594
Email: biaph@biaph.com
Website: www.biaph.com

Peterborough Area
Brain Injury Association Peterborough Region
Phone: 705-741-1172 or 1-800-854-9738
Email: biapr@nexicom.net
Website: www.biapr.ca
Sarnia-Lambton
BIA of Sarnia-Lambton
Phone: 519-337-5657
Email: sarnia.biasl@gmail.com
Website: www.sarniabiasl.ca

New Beginnings ABI & Stroke Recovery Association
Phone: 519-491-2668
Email: info@newbeginnings-cksl.com
Website: www.newbeginnings-cksl.com

Sault Ste. Marie
BIA of Sault Ste. Marie & District
Phone: 705-971-1050
Email: braininjuryssmd@gmail.com
Website: www.soobraininjury.com

Sudbury and District
BIA of Sudbury & District
Phone: 705-670-0200
Email: info@biasd.ca
Website: www.biasd.ca

Thunder Bay
BIA Thunder Bay & Area
Phone: 807-621-4164
Email: biatba@yahoo.ca
Website: www.bisno.org/brain-injury-association-of-thunder-bay.php

Timmins
Seizure & Brain Injury Centre
Phone: 705-264-2933
Email: sabicrl@eastlink.ca
Website: www.seizureandbraininjurycentre.com

Toronto (GTA)
Brain Injury Society of Toronto
Phone: 416-830-1485
Email: info@bist.ca
Website: www.bist.ca

Waterloo-Wellington
BIA of Waterloo-Wellington
Phone: 519-654-0617
Email: info@biaww.com
Website: www.biaww.com

Windsor-Essex
BIA of Windsor and Essex County
Phone: 519-981-1329
Email: info@biawe.com
Website: www.biawe.com

York Region
Brain Injury Association of York Region
Phone: 905-780-1236
Fax: 905-780-1524
Email: n/a
Website: www.biayr.org

Provincial Associations

Brain Injury Canada/Lésion Cérébrale Canada
Phone: 613-762-1222, Toll free Line: 1-866-977-2492
Email: info@braininjurycanada.ca
Website: www.braininjurycanada.ca

British Columbia Brain Injury Association
Phone: 604-984-1212
Email: info@brainstreams.ca
Website: www.brainstreams.ca

Central Alberta Brain Injury Society (CABIS)
Phone: 403-341-3463
Email: cabis@telus.net
Website: www.cabis.info

Saskatchewan Brain Injury Association
Phone: 306-373-1555 or Toll free (in Sask) 866-373-1555
Email: info_sbia@sasktel.net
Website: www.sbia.ca

Manitoba Brain Injury Association
Phone: 204-975-3280 or Toll Free: 866-327-1998
Email: info@mbia.ca
Website: www.mbia.ca

Ontario Brain Injury Association
Phone: 905-641-8877 or 1-855-642-8877
Toll free support 1-800-263-5404
Email: obia@obia.on.ca
Website: www.obia.ca

Newfoundland and Labrador Brain Injury Association
Phone: 709-579-3070
Email: nlbia2011@gmail.com
Website: www.nlbia.ca/index.php

Regroupement des associations de personnes traumatisées cranio-cérébrales du Québec
Phone: 450-575-8227
Email: info@raptccq.com
Website: www.raptccq.com

Brain Injury Association of Nova Scotia
Phone: 902-473-7301
Email: info@braininjuryns.com
Website: http://braininjuryns.com/

Brain Injury Association of Canada (New Brunswick)
Phone: 506-721-8003
Email: biacnb@icloud.com
Website: www.biacnb.org

Brain Injury Association of P.E.I.
Phone: 902-314-4228 or 902-367-3216
Email: info@biapembali.com
Website: www.biapembali.com
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Ground Floor
Hamilton ON
L8N 3W1
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Hotel: Four Points by Sheraton, Ph: 905.984.8484

Professors: Sherrie Bieman-Copland, Ph.D, C.Psych
Dawn Good, Ph.D, C.Psych

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www.oatleyvigmond.com/roger