**Board of Directors**
Jean-Baptiste Arhanchiague, Doris Barkley (Vice President), Robert Brown (Representative to Autism Society of Canada Board), Janet Culliton, Susan Fitzhenry, Dr. Kassia Johnson, Gail Laliberte (Secretary), Carole Ann MacDonald, Joseph McDonald (Treasurer), Amanda McNulty, Leah Miltschin (Past President), Dr. Jo-An Reitzel, Kim Seabrook (Chair-President’s Council), Cathy White (President)

**Local Chapters**
To find contact information for your local Autism Ontario chapter, visit www.autismontario.com.

---

**Autism Ontario**
1179 King Street West, Suite 004
Toronto, ON  M6K 3C5
Phone: 416-246-9592
Fax: 416-246-9417
mail@autismontario.com

Autism Ontario is a registered charitable non-profit organization (#11924 8789 RR0001).

**OUR VISION:** Acceptance and opportunities for all individuals with Autism Spectrum Disorders (ASD). Our Mission: To ensure that each individual with ASD is provided the means to achieve quality of life as a respected member of society.

**Autism Matters** is published four times per year. Autism Matters welcomes contributions from its readers. Send your articles, reviews, letters, comments, announcements, etc., to Margaret Spoelstra, Autism Matters Editor. For advertising rates and inquiries contact GEPM Group Inc., info@gepmgroup.com. Inclusions of information not directly related to Autism Ontario are for information only and individuals, events, therapies, treatments, etc., are not necessarily endorsed by Autism Ontario.

---

**What’s Inside**

**SPRING/SUMMER 2013**
**SPECIAL WORLD AUTISM AWARENESS DAY ISSUE**

### features

<table>
<thead>
<tr>
<th>Page</th>
<th>Title</th>
<th>Authors</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>An Act Respecting World Autism Awareness Day</td>
<td>by The Honourable Jim Munson</td>
</tr>
<tr>
<td>8</td>
<td>Magnusmode</td>
<td>by Nadia Hamilton</td>
</tr>
<tr>
<td>9</td>
<td>World Autism Awareness Day, Raise the Flag – April 2, 2013</td>
<td>by Katharine Buchan</td>
</tr>
<tr>
<td>17</td>
<td>Ontario Families and Financial Pressure</td>
<td>by Rick Machtinger</td>
</tr>
<tr>
<td>19</td>
<td>Learning to Get Along</td>
<td>by Laura Dignard</td>
</tr>
<tr>
<td>22</td>
<td>Kidnastics</td>
<td>by Rachele Hosten</td>
</tr>
<tr>
<td>24</td>
<td>Scholarships</td>
<td>by Doris Barkley</td>
</tr>
<tr>
<td>28</td>
<td>Autism Ontario’s 40th Anniversary and the Scotiabank Walk</td>
<td>by Rick Machtinger</td>
</tr>
<tr>
<td>30</td>
<td>I Have Autism and I Need Your Help: A Series</td>
<td>by Teresa and Erik Hedley</td>
</tr>
<tr>
<td>34</td>
<td>It’s SUPER-MAX to the rescue!</td>
<td>by Joel Rubinoff</td>
</tr>
<tr>
<td>36</td>
<td>Stranger in a Strange Land</td>
<td>by Kevin Reinhardt</td>
</tr>
<tr>
<td>38</td>
<td>Surf’s Up!</td>
<td>by Brad Cotton</td>
</tr>
<tr>
<td>40</td>
<td>Top 10</td>
<td>by Michelle Reddick</td>
</tr>
<tr>
<td>42</td>
<td>Winnie-the-Pooh and Me</td>
<td>by Lisa Vezeau-Allen</td>
</tr>
<tr>
<td>54</td>
<td>Bullying</td>
<td>by Scott Smith</td>
</tr>
<tr>
<td>39</td>
<td>New Autism Advocacy Network</td>
<td></td>
</tr>
<tr>
<td>40</td>
<td>In Your Corner</td>
<td></td>
</tr>
<tr>
<td>42</td>
<td>First Lego® League – The Explosive Legobots – Sudbury</td>
<td>by Chanda Gryllis-Mahaffy</td>
</tr>
</tbody>
</table>

---

**info autisme**

<table>
<thead>
<tr>
<th>Page</th>
<th>Title</th>
<th>Authors</th>
</tr>
</thead>
<tbody>
<tr>
<td>44</td>
<td>Le trouble du spectre de l’autisme (TSA) et l’anxiété</td>
<td>par Anne Borbey-Schwartz</td>
</tr>
<tr>
<td>46</td>
<td>À l’aventure avec Savon Quilave !</td>
<td></td>
</tr>
<tr>
<td>48</td>
<td>Zacada Circus School</td>
<td>par Chantal Mudahogora</td>
</tr>
<tr>
<td>50</td>
<td>Journée mondiale de sensibilisation à l’autisme</td>
<td>par Jean-Michel Bédard</td>
</tr>
<tr>
<td>51</td>
<td>Ressources</td>
<td></td>
</tr>
</tbody>
</table>

Cover photo: The Canadian Flag and Autism Ontario flag flying at the City of Kawartha Lakes Lindsay Library on April 2, 2013 to commemorate “Raise the Flag” day in Ontario. Photo credit: RoseMarie Condon.
columns

3 News and Noteworthy
55 Board Corner, by Leah Miltchin
56 Who’s Who on our Board – Janet Culliton
58 ACSF:SC Project Update III
60 In Your Corner, by Erin Roza and Katherina Symes

book reviews

53 The Spark: A Mother’s Story of Nurturing Genius, by Kristine Barnett, reviewed by Monica Richardson

Editor’s Note: Inside the pages of Autism Matters we try to include a range of views about ASD and its impact on people. These views may or may not reflect our own, but we trust that diversity of views adds to the reader’s insight about complex issues.

poems

62 The Invisible, by Nancy Getty

Strategic Directions
Look for these icons to identify articles in this issue with aspects of Autism Ontario’s strategic priorities:
1 Effective marketing and fundraising
2 Building a unified organization
3 Opening doors for adults
4 Educating educators and professionals
5 Using information technology to collaborate, learn and share
6 Expanding our reach
THE SPRING/SUMMER 2013 edition of Autism Matters represents another valuable experiment in publishing the only regular magazine dedicated to issues related to ASD in Canada. This time we’ve combined the two issues – Spring and Summer and also highlighted World Autism Awareness Day 2013 activities. Wasn’t that a party! With over 300 municipalities raising the Autism Ontario flag on April 2, and numerous events drawing attention to people with ASD and their families, we are grateful for the Bank of Montreal’s support and the inspiration from key families’ partnership with us. This was such a success that we hope to expand this event to Ontario schools in 2014. Watch for news about this in our Fall 2013 issue.

It’s hard to know what to advise you to focus on in this issue because it is jam-packed with encouraging stories, relevant/current/useable information and opportunities that continue to present themselves to us through relationships right across Ontario and beyond.

Autism Ontario is in the midst of reviewing its strategic directions and celebrating what we’ve achieved in the past three years against the backdrop of our 40th anniversary. But while we’re doing that, we are also keenly aware of what remains undone. The Telford family story provided us with a sharp reminder about the needs of our aging population on the autism spectrum and to continue to advocate for earlier, timely and specific tailored supports to individuals and their families in local communities.

Although we hope you have a chance to put your feet up and read through these pages over a cool beverage this summer, please know that we are working hard to prepare for the anticipated release of the Ontario Ombudsman’s report this fall, waiting for news of progress on the Provincial Auditor’s report on autism services for children and youth, and the Province’s Experts Panel on ASD chaired by Dr. Ian Dawe. Autism Ontario is also honoured to be part of a team of parents and organizations producing a report on the housing needs of adults with developmental disabilities in Ontario due for release and subsequent action this summer.

And then there are camp programs! Over 1,000 children with ASD are being supported to attend summer programs this summer through Autism Ontario with financial support from MCYS, private donations and grant funds working together with our volunteers, staff and partners throughout Ontario. And if you’re in Toronto this summer, be sure to check out the Aloha Toronto and Marque d’Elegance event on the August 23-25 weekend.

We welcome your feedback on this massive issue of Autism Matters. See you in September.

Marg Spoelstra
Executive Director
WHAT IS THE BEST ESTIMATE OF THE PREVALENCE OF AUTISM SPECTRUM DISORDERS IN CANADA?

The National Epidemiologic Database for the Study of Autism in Canada (NEDSAC) has been monitoring the prevalence of autism spectrum disorders (“autism”) in Newfoundland and Labrador, Prince Edward Island and Southeastern Ontario since 2003. Based on information from our most recent year of data collection (2010 in Prince Edward Island and Southeastern Ontario; 2008 in Newfoundland and Labrador), our best estimate of the prevalence of autism spectrum disorders in Canada is 1 per 94 children.

What does “prevalence” actually mean, and how is it calculated?
The prevalence of a condition refers to what proportion of the population has that condition at a certain point in time. For NEDSAC, the prevalence of autism is reported on a calendar-year basis. Our prevalence estimates were calculated by dividing the number of children identified with autism who lived in the surveillance region (e.g. Prince Edward Island) at any time during a given year by the total number of children who lived in that region in that year.

What age group is the 1 in 94 figure based on?
Since individuals with autism often are not diagnosed until they reach school age, the estimate above is based on children 6 to 9 years of age.

Why don’t you report the prevalence for 8-year-olds, like the Centers for Disease Control and Prevention does in the United States?
Our population in Canada is much smaller than that of the United States. We can get more reliable estimates by reporting the prevalence for an age group rather than a specific age.

Is the prevalence of autism increasing in Canada?
The prevalence of autism does appear to be increasing, based on the information we have collected since 2003. You can view a full report of our findings at www.nedsac.ca under Publications → Reports.

For more information, please contact:
Hélène Ouellette-Kuntz, PhD
NEDSAC Director and Associate Professor
Department of Community Health and Epidemiology, Queen’s University
Tel: 613-548-4417 x 1198
Email: helene.kuntz@queensu.ca
GOOD MORNING, HONOURABLE COLLEAGUES, and heartfelt thanks for inviting me to appear before your committee as a witness regarding Bill S-206, An Act respecting World Autism Awareness Day.

As you might know, this bill has had quite a journey since I first introduced it four years ago. Two prorogations and one general election are among the events that complicated what should have been a straightforward passage.

Being parliamentarians, we just have to roll with circumstances like these and remain optimistic and determined. As it happens, despite all the setbacks, I have been tremendously encouraged by the reception this little bill has received at various stages and from all parties throughout its circuitous journey. It would not be where it is today, attending consideration by your committee, were it not for all the individuals here on the Hill and throughout this country who recognize the implications of and the need to address the mounting autism crisis.

On October 19, 2011 – almost exactly one year ago – I stood in the Senate Chamber to move second reading of this bill. I felt it was important on that occasion to recognize some of the people who have supported this bill and efforts to help Canadians become more sensitive to the realities of autism. Notable supporters from the Senate include Senators Eggleton, Oliver, Mercer and former Senators Keon and Trenholme Counsell.

MP Mike Lake and I have talked a lot and we have shared many experiences. You were no doubt moved as I was when he last stood in the House Chamber to support this bill and talked about his home life with his teenage son, Jaden, who is autistic. No one but a parent can help us really understand the day-in, day-out challenges of raising a child with this complex disorder.

At second reading of this bill in the House in June, MPs and other representatives contributed their insights to discussions about the significance of this bill. Mr. Harold Albrecht, described how people with autism and their families face ongoing stigma and lack of understanding about their daily struggles. In the past, he has also spoken persuasively about the need to bring together researchers, clinicians, policy-makers, parents and other key stakeholders to identify effective treatment and diagnostic techniques.

Dany Morin, who brings so much to this committee, covered the key strategic issues related to autism. These include the necessity for all levels of government to support research on the real causes of Autism Spectrum Disorders – ASDs. I couldn’t
agree more with his vision of preventing them through medical advances and what that would mean for families.

Jacques Gourde reminded those present of the Canadian adolescents and adults with autism who did not have the benefit of early diagnosis and prompt treatment. Illustrating just how important it is to have easy access to reliable information, Mr. Gourde described their experiences: “Teenagers are all too aware of their limitations and differences, which can make them feel marginalized, vulnerable and isolated.”

It’s been 10 years since my eyes were first opened to autism – how difficult life can be for children with autism and their families. It began with a chance encounter not far from where we are today. As I was walking up the Hill to my office, my eyes were somehow drawn to a man who was quietly “protesting,” for lack of a better word, for support for his autistic son. I stopped to listen to what he had to say about his life, and what I learned from him was life changing.

That encounter marked a beginning for me. A point where I realized I wanted to find out more about this disorder and make a positive difference.

Though in those first years public awareness about autism was generally very low, my efforts to change that were typically met with wonderful receptivity here on the Hill. The Senate Committee on Social Affairs, Science and Technology easily recognized the need to investigate the disorder, and undertook a lengthy, comprehensive study. In March 2007, the committee released its report on that study, Pay Now or Pay Later – Autism Families in Crisis.

Most of you are likely well versed in the recommendations set out in that important document. Among all of them, our call for a comprehensive national strategy for ASD has stirred the most compelling and enduring debate. Other recommendations included a national public awareness campaign implemented by the federal government, and funding for the creation of a knowledge exchange centre.

With the tabling of the report, autism advocates across Canada flew out of the starting gate in support of its recommendations – fixing in particular on a national strategy as the only moral and effective response to the autism crisis.

We have national strategies for heart disease, diabetes and cancer. Why not autism? With each passing day, the need for greater federal commitment to addressing this health crisis becomes greater and greater.

I have travelled from coast to coast, meeting with groups and individuals working within their communities, their home provinces and at the federal level to strengthen Canada’s capacity to deal with autism. I know that in fulfilling your orders of reference, you have in the past met with and heard testimony from some very knowledgeable, experienced people from the Canadian autism community. I’m sure I don’t need to convince you of their distinct dedication to the cause – a dedication rooted in the plight – but momentum is nonetheless building.

There are just so many compelling and critical facets to the topic of autism that we might discuss today. But before we move into the discussion stage of this hearing, I would just like to make a few remarks about the intention for Bill S-206 – An Act respecting World Autism Awareness Day.

Over the past decade, wherever my involvement in this cause has taken me, there is one thing that I hear repeatedly. It never changes. People with autism and their families are isolated.

Isolation is, of course, one of the principal characteristics of autism. But the disorder also isolates the families and friends of people with autism.

Constant care is often required. This can mean that in a two-parent family, one person stays at home full time and looks after the child with autism. This parent has a heavy burden, which is not easily mitigated by typical opportunities to socialize. Birthday parties, playgroups, play dates, trips to the library or the mall, and even an afternoon in the park. These activities can be exhausting and demanding.

What the families of autistic children...
yearn for are the kinds of experiences most families take for granted: That their son or daughter through whatever therapy helps can have a sleepover just like any other child.

The cost of care, much of which is not covered by provincial programs, may require that family earners take on a second job. This brings on more isolation and more family stress. Families are breaking apart. The load of autism is frequently too much to bear.

Though this is a common scenario, it is only one. There are countless troubling stories that can be told about the families of autistic children. Financial strain, fatigue and constant worry. Waiting for months and even years for a child’s name to move up on a waiting list for diagnosis, treatment and care.

This bill to respect World Autism Awareness Day will not change their reality, but it will send out a message they deserve to hear. It will say to these children and their families, “you are not alone.” It will show these families that their plight matters. That the people of Canada respect and admire them for doing the best they can in the name of their children, brothers, sisters, grandchildren, nieces and nephews.

World Autism Awareness Day will help build awareness among Canadians about autism – its symptoms, the people who are affected by it, and the need to address the crisis it has become.

Just as this day would engage individuals and society, so too would it empower governments to do even more. It would be my wish to see the federal government increase its involvement, where the need is greatest – for instance funding and programs for aboriginal children.

My former colleague, Dr. Keon, always had good advice for me. He knows so much. He told me to keep pushing for a federal role in science and research. World Autism Awareness Day would be the ideal opportunity to get this message out.

I am grateful to all of you – Madams Chair and Vice Chair, and all the esteemed members of the Health Committee – for the consideration you are giving this bill and the people who represent its purpose. I look forward to hearing your comments and addressing any questions you might have.

**THERE ARE MANY YOUNG PEOPLE** across Ontario and around the world for whom the concepts of independence and inclusion are dreams and aspirations rather than rights of passage. Magnusmode is an innovative new company dedicated to changing fate. Specifically, it utilizes a unique combination of Applied Behaviour Analysis and principles of video game design to engage the strengths and interests of individuals with autism and enable them to achieve greater independence. As its Founder, I grew up with a very close relationship to a brother with autism (Troy) and have worked for more than five years with families affected by ASD. My love and admiration for Troy, coupled with my desire to empower all young adults with special needs, is the driving force behind this initiative.

Magnusmode is partnered with Centennial College, and recently Toronto Police Service to achieve this worthwhile pursuit. This July, Magnusmode is partnered with Autism Ontario York Region to pilot the program through facilitated activity sessions in Autism Ontario summer camps.

Activity sessions will leverage the Magnusmode program to support weekly activities such as going to the movies, grocery shopping, cooking and lifeskills activities. This program features the character of Magnus, a quirky, fun and likeable hero that guides the user through day-to-day challenges on customizable web and mobile platforms. The goals of this collaboration are to enhance the camp experience, record the usefulness of this tool for people across the autism spectrum and involve individuals with autism and their parents in the creation of a tool that is truly useful to them. Troy and I, along with the team at Centennial, and of course Magnus, look forward to working together with Autism Ontario to lead fun educational experiences in a variety of community settings.

At the heart of this mission are the families affected by autism. Magnusmode believes in engaging the entire community to work together to build effective resources that dramatically – and permanently – support the needs of people with autism.
World Autism Awareness Day, Raise the Flag – April 2, 2013
by Katharine Buchan

On the City Hall rotunda in Toronto, a waiting crowd had drawn together and was standing arm-in-arm as an Autism Ontario flag inched its way up the flagpole.

As soon as Toronto Councillor Shelley Carroll, a representative of Ward 33 (Don Valley East), had officially proclaimed the day, the 100 or so people broke apart to hug one another, or shake hands, or snap pictures, smiling and laughing all the while.

IN THE MOMENT OF CELEBRATION, a small woman, bundled up warmly against the cold of early April, approached me. With tears in her eyes, she gently touched my arm and whispered, “Thank you.” I smiled, thanking her for coming out. She explained, “My grandson has autism and the attention Autism Ontario has generated today because of this flag-raising ceremony has been so essential in helping to bring awareness of how families are affected by autism. The work you do is so important.” I thanked her again, this time for her generous words. She nodded and I watched her slip quietly back into the crowd.

I was not alone in experiencing such a powerful moment. At noon on April 2, 2013, flags went up across Ontario in honour of the first official World Autism Awareness Day.

An Idea Is Born
The idea was born in St. Thomas, Ontario, where Bailey Bishop-Hume had been diagnosed with Autism Spectrum Disorder when she was two-and-a-half years old. In 2010, the Bishop-Hume family gathered with their community on April 2 to promote autism awareness with their first annual flag-raising ceremony. A passionate group of community members, advocates and professionals picked up on what the Bishop-Humes were doing and developed the idea of holding flag-raising ceremonies across the province. Because of its strong presence within Ontario communities, Autism Ontario was invited to take part. Soon after, the Bank of Montreal (BMO) recognized the historic nature of the Raise the Flag event and generously partnered with Autism Ontario, as part of its ongoing commitment to improving communities.
The idea grew into a bill to officially declare April 2 World Autism Awareness Day (WAAD). Dedicated and determined Autism Ontario Chapter staff, Autism Ontario volunteers, Family Support Coordinators and Community Events Coordinators set to action, inviting Ontario’s municipal and provincial leaders to participate. BMO generously contributed to covering the cost of manufacturing special Autism Ontario flags to fly on April 2, and BMO staff volunteered their time and resources to assist in the creation of awareness packages and print materials. Participating municipalities were equipped with a flag, an official proclamation and some advance excitement and publicity, which included WAAD radio announcements created by Rick Grylls from the Sudbury Chapter and interviews on 99.5 The Moose FM with Community Resource Manager Katherina Symes, which played across the central and northeast sections of Ontario. Chapters across the province mobilized their members through Facebook and tweets were sent out inviting the public to get involved. There was a genuine excitement in the air.

The Day Arrives
Once news of the provincial event began to spread, community organizations began to request the chance to “Raise a Flag” for WADD on April 2 too. Some of these organizations included emergency services, hospitals, the main offices of several school boards plus individual schools, public libraries, Johnson & Johnson, and Erin Oaks.

Individuals took the coming event into their hearts, too. Dana Larrett had just revealed his diagnosis to her son Lucius on April 1. When asked for her thoughts on the events of April 2, Dana mentioned she woke up with a flutter in her heart. “Today was a day of recognition for those families and persons affected by autism; a day we come together and stand proud for our loved ones and also share the joy of their success in life as a whole” she said. “I felt like a proud peacock with my feathers spread wide, standing tall, with love in my heart for all those who were able to support our flag raising and celebrate this monumental day for all to see!” The family all wore their WAAD T-shirts, in which Lucius, for one, felt like “a rock star.” Dana says, “he told everyone that asked [that the day] was for him!”

Official Involvement
April 2, 2013 provided community leaders an opportunity to publicly support families touched by autism across the province. City councillors, MPs and MPPs, along with autism service providers and emergency services, attended the ceremonies. Speakers included the Minister of Child and Youth Services, Teresa Piruzza, who attended the Windsor flag-raising ceremony.

Says Rita Miceli, a Windsor parent: “[I]t truly was an emotional moment to watch my son [Gaici Miceli] raise the Autism flag proudly at our city hall in front of the Mayor of Windsor, Eddie Francis, Minister Teresa Piruzza, many city councillors and school officials, family and friends. This unforgettable moment signifies how autism awareness has risen profoundly and gained momentum in our local community.”

Having “the talk” with your child on the spectrum
In the weeks leading up to April 2, 2013, Dana Larrett thought long and hard about the idea of having “the talk” with her son Lucius. She wondered how he was going to feel when she explained autism to him. She weighed whether introducing his diagnosis to him now, at age 6, or when he was older was the right thing for Lucius. She wondered if he might use his diagnosis as a crutch or an excuse. She wondered if he would understand. Thoughts bounced around in her head, but Dana was certain of one thing; she did not want her son to hear about his diagnosis from someone else or have someone else ask him something which could potentially be troublesome.

On the evening of April 1 Dana found herself and Lucius tucked together on their loveseat enjoying some quiet time together. Dana realized this moment was the perfect opportunity to have the talk. She introduced the word autism out loud and did her best to explain how this term affected Lucius. To her surprise, Lucius looked relieved. Dana began to cry as she realized her child “was just waiting for some understanding as to why he struggled[ed] with certain elements.” Lucius was not upset and told Dana he loved her “very much!” Dana reassured Lucius that she would always be there for him, “to help guide his way and celebrate all his successes. LOUD and PROUD!”

Dana fell asleep on the eve of World Autism Awareness Day “with a clear conscience” and “only a tidbit of trepidation” in her heart “for the entire splendour that was yet to come.”
Christina Daguerre, a parent of a child with autism in Timmins, ON, agrees. “As a parent, I was touched to learn that communities across Ontario were able to spread awareness for autism in this fashion. I was overwhelmed with pride as I watched my son Dominic proudly raise the Autism Ontario flag with the help of our mayor, Tom Laughren.

« Comme parent, la levée du drapeau d’Autisme Ontario à Timmins, m’a touchée énormément. J’étais débordante de fierté en voyant mon garçon Dominic lever le drapeau avec l’aide du maire, Tom Laughren. Merci à Autisme Ontario qui, par cette initiative, a fait en sorte que toutes les communautés de l’Ontario puissent participer à cette activité de sensibilisation à l’autisme. »

In Toronto, Ontario Ombudsman André Marin attended the ceremony at City Hall. Cynthia Park, a parent in Toronto, described how important it was to have such public officials participate in the “Raise the Flag” event: « Il était extrêmement agréable de voir André Marin, Adam Vaughan, et tant d’autres personnes qui sont venues pour WAAD. Un grand merci à Mme Romanov pour l’avoir organisé! Cei pourra signifier que des services offerts directement aux familles seront rendus disponibles au lieu de créer des listes d’attente, des positions administratives et téléphoniques qui ultimement sont inutiles aux familles. »

Chapter Stories

Feelings of pride in their members and gratitude for their community’s whole-hearted participation is something many chapter participants across Ontario described. Rory Scheuneman of the Chatham-Kent Chapter shared: “[We] received news coverage all day from Blackburn Radio, and we also had an awesome family profile story published by Sun Media in the Chatham Daily News, profiling two of our chapter families and their day-to-day challenges of raising children with ASD. The C-K Chapter also partnered with other agencies and businesses in the area and had an online auction and other events to raise awareness for autism. The best part of the day was that we reached two new families in the Chatham-Kent area that were facing the same challenges. What a great day and a successful event; just a start of bigger things to come!”

Tracy Davidson, Manager of Chapter Development and Fundraising for the Ottawa Chapter, pointed out that the special day “was a great opportunity to build relationships and raise awareness about individuals living with autism in both large and small municipalities.”

Mimi Golding in Ottawa shared her thoughts about the importance of World Autism Awareness Day for individuals with ASD. « La Journée mondiale de l’autisme est importante puisqu’elle permet d’attirer l’attention sur un groupe de personnes qui a besoin de services, de soutiens et de compréhension. Elle contribue à faire connaître le diagnostic de trouble du spectre de l’autisme à un plus vaste public et, par le fait même, à susciter dans la population des attitudes de patience, de bienveillance et de compassion.»

In Akwesasne, Mohawk Territory, located in eastern Ontario, Pascale Aubut-Delormier asked the local branch of the Bank of Montreal to host the flag-raising ceremony. The branch was so impressed with the excitement and
Top left: Jenne Wilson and Owen Lamothe celebrate WAAD in Sudbury. Photo credit: Unknown
Top centre: Councillor Shelley Carroll proclaims April 2, 2013 World Autism Awareness Day in the City of Toronto. Photo credit: Marti Veliz
Top right: Windsor Mayor Eddie Francis and Gaici Micelli pose outside Windsor City Hall. Photo credit: Patrick Roberts
(Inset) Minister of Child and Youth Services, Teresa Pinuzza in Windsor, ON. Photo credit: Patrick Roberts
Middle: Akwesasne celebrates WAAD. L-R: Joryan, Jaylan, Teharakwaneken and Chantal.
Top: Debbie Terrance, Norma Sunday, Shelby Mitchell-Adams, Jaiden Mitchell, Pascale Aubut-Delormier, Niohontesha Jacobs and Cindy Evans. Photo credit: Pascale Aubut-Delormier
Bottom: Timmins celebrates “Raise the Flag.” Top Row (L-R): Lisa Malette, Judith Lamothe, Geneviève Bureau, Samantha Bliss
Middle Row (L-R): Cindy-Lee McCombe-Hooker, Lindsay Gagnon, Chantal Janson, Sarah Robinson, Christina Daguerre, Dominic Daguerre and Mayor Tom Laughren
Right of flag (L-R): Chantal Quesnel, Catherine Simunovic.
enthusiasm that the event generated they agreed to fund the ceremony next year. Pascale took the opportunity to share some information about ASD with the local Boys and Girls Club and to highlight the serious gaps in services for children, youth and adults living with ASD in her Mohawk community. As Shelby Mitchell-Adams, a parent with a child with autism, expressed the situation very appropriately:

“lab tatekakasbions ne oia nikuwiroten. Onen senba waokenta’ne ne ratiksakona: ne Aabkwasabane ratinake:re tanon ne teiokwata'acon. Kenthon se’kaien tanon onen ia’kabe:we ne aieithiriwa:we ne oia nikuwiroten. Tewaribwaketsko ne taioiwate’nehak ne ratiksoko’:a ne Aabkwasabane ratinake:re.”

Or, in English (as translated by Rosemary White): “Autism doesn’t discriminate. It’s here in our community and we as Mohawk of Akwesasne are noticing an increase in autism rates as well as in our surrounding areas. It is here and we must come together for services and treatments. Let’s create a brighter future for children of Akwesasne.”

Plenty of Coverage
The events of April 2 and related stories were covered in countless newspapers, online journals and newsletters across Ontario, including the Beacon Herald in Stratford, the Ministry of Children and Youth Services Autism e-Newsletter/Bulletin, Holder’s Happenings in Windsor, the Tillsonburg News, Canada AM, the Chatham Daily News, the Toronto District School Board Newsletter and the Toronto Catholic District School Board newsletter.

Meanwhile, back in St. Thomas, the Times-Journal featured the Bishop-Humes’ flag-raising celebration – now duplicated more than a hundredfold – as its front-page feature. This family’s simple yet powerful message to their community had truly taken wing. The flags now snapping in the April breeze in front of hundreds of city halls, schools, libraries, banks, businesses and emergency services in municipalities across the province were connecting families touched by autism across Ontario and will be a colourful symbol of Canada’s official recognition of April 2, World Autism Awareness Day, for years to come.

After all the celebration, sharing, connecting and understanding had tapered off in the rest of the province, in Toronto, World Autism Awareness Day continued with a sold-out fundraising event at the Brazen Head Pub that raised more than $10,000 for Autism Ontario.

The evening featured five celebrated guests, ably introduced by Deborah Wasaga Beach raises a flag in honour of World Autism Awareness Day. L to R: Town councillors Morley Berkavitch, Ron Anderson, George Watson and Mayor Cal Patterson.
feature AUTISM AWARENESS

Top: Inside the City of Kawartha Lakes Lindsay Library. The powerhouse advocates in Lindsay invite the public library and the Kawartha Lakes Police Department to “Raise a Flag” in honour of WAAD. L-R: Provincial Constable Carrie Lanning, OPP; Donna Thomson, Chairperson, Lindsay Asperger Autism Support; Nicole Corriveau, Graphic and Web Designer; Hellen Francis, Co-Chairperson and Autism Ontario Potential group representative; Lynda Amting, Secretary-Treasurer. Photo credit: Rose-Marie Condon.

Bottom left: Ajax Mayor Steve Parish and Ana Marple, a member of the Durham Chapter CLC pose below the flag at the “Raise the Flag” ceremony in Ajax. Photo credit: Christa Sawyer.

Bottom right: Ajax in Durham Region. L-R: Councillor Joanne Dies (Ward 3, Ajax), Mayor Steve Parish (Ajax), Ana Marple (Durham CLC) and Christa Sawyer (CEC, Durham and Peterborough). Photo credit: A parent attending the ceremony.
Kitchen, an autism parent and advocate. The guests included *New York Times*’ bestselling authors Lisa Genova and Andrew Solomon (*Love Anthony* and *Far From the Tree*, respectively) and world-renowned research scientist Dr. Steve Scherer, in a panel discussion moderated by Beverly Thomson, Co-Host of CTV’s breakfast show, *Canada AM*.

The discussion was informative and thought-provoking – a wonderful finish to an altogether inspiring day. Attendee Janet Blanchard was excited by the themes of parenthood explored by the panelists. “The speakers were fabulous and informative; they really gave us all a reminder of how to be a better person/parent. Parenthood is challenging as it is; God bless and give strength to those amazing parents who love, raise and nurture their unique and special children. They/you are an inspiration to us all.”

Martha Gruentzer enjoyed the differing points of view presented by the panel members. “I really enjoyed most listening to the perspective of the speakers. I don’t have very much knowledge of autism and it was fascinating for me to learn more about it. I read *Love Anthony* last week and purchased *Far From the Tree* last night and am looking forward to reading it.”

Top: Toronto celebrates WAAD in front of City Hall. L-R: City Councillor Paula Fletcher (Ward 30); James Kelsey (BMO) with his son’s family; Martha Carroll; City Councillor Shelley Carroll (Ward 33); City Councillor Adam Vaughan (Ward 20); Councillor Janet Davis (Ward 31); and City Councillor Gord Perks (Ward 14).

Middle: The Toronto District School Board celebrates the “Raise the Flag” event in Toronto. L-R: Donna Quan, Director of Education; Ginny Pearce, TDSB Autism Ontario SEAC member; Sandy Spyropoulos, TDSB Superintendent of Education; Margo Ratsep, TDSB SEAC Liaison and Paula Fletcher, City Councillor.

Bottom: Thunder Bay comes out to “Raise the Flag” in support of WAAD outside City Hall. L-R: Lucius Larrett, Dana Larrett, Tanja Vance, Ashley Blundon, Laura Sylvestre, Shauna Murphy-Crupi, Tony Crupi, Michaela Crupi.

Photo credits: Marti Veliz.
Andrew Garrett recognized the significance the event: “Thank you for inviting me to the event! I was fascinated by the guest speakers, and it was a privilege to hear testimonies from you and others who have been touched by autism. Thank you for including me in this historic event!”

Jana Levin sums it up nicely: “This was a very moving, meaningful evening and one of the best autism events I have attended.”

Top: Laura Sylvestre and her son, Gareth, attended the “Raise the Flag” ceremony in Thunder Bay. Photo credit: Michelle Murdoch-Gibson
Inset: The Niagara Region Chapter celebrates World Autism Awareness Day by hosting the first community partners breakfast aimed at spreading autism awareness.
Middle: Cheers outside the City of Kawartha Lakes Library as the “Raise the Flag” ceremony takes place. Mayor Ric McGee; Donna Thomson, Chairperson, Lindsay Asperger Autism Support; Provincial Constable Carrie Lanning, OPP; John Hagerty, Chief of Police, Kawartha Lakes Police Service; City Councillor Gord James; City Councillor Patrick O’Reilly; Terry Cox, Administrative Sergeant, City of Kawartha Lakes Police Service. Standing behind the Mayor is a city worker, name unknown. Photo credit: RoseMarie Condon.
Bottom left: The Canadian flag and Autism Ontario flag fly at the City of Kawartha Lakes Lindsay Library on April 2, 2012 to commemorate “Raise the Flag.” Photo credit: RoseMarie Condon.
Ontario Families and Financial Pressure

HELPING TO PROVIDE FINANCIAL STABILITY TO FAMILIES OF CHILDREN WITH SPECIAL NEEDS

by Rick Machtinger BBA, MBA, CFP

Families with Special Needs Children often rely on the Medical Tax Credit to provide relief for some of the associated costs; however, with a maximum eligible tax credit of less than 20 percent of the total expenses incurred (once a threshold is exceeded), relief provided by the Medical Tax Credit in Ontario is insufficient.

Given the considerable health costs these families may incur, it may be helpful to educate them on a little known, but highly effective financial vehicle called the Health Spending Account.

The Health Spending Account – Providing Relief

The Health Spending Account is currently recognized by the Canada Revenue Agency and allows members to pay for health expenses using pre-tax dollars. There is no set-up fee, and funds do not expire.

Health Spending Accounts (or Health and Welfare Trusts) were first introduced in 1986 when Finance Minister Paul Martin presented a new way for businesses to
offer health benefits to their employees. Until recently, the use of HSAs has been limited to larger companies that have the resources to understand and properly administer these plans. Today, technology has simplified HSA administration to such a degree that the Health Spending Account is a practical consideration for the majority of workers and employers in Ontario.

Eligible Medical Expenses Under the HSA

Health Spending Accounts are the government’s way of helping families to afford and manage their healthcare expenses. In recognizing that each family is unique in their needs, the list of eligible HSA expenses in Ontario is extensive, including diagnosis and treatment services for special needs children.

The Canada Revenue Agency has spent over two decades developing the essential Health Spending Account guidelines. The definition of a Health Spending Account eligible expense is as follows: *Any health related expenditure prescribed, performed, administered or supervised by a licensed medical practitioner.*

**HSA’s: Helping Families Cope With Special Needs Diagnosis and Treatment**

Health Spending Accounts have been helping families and individuals cope with the financial pressures associated with the diagnosis and treatment of a special needs child by providing financial relief for a variety of the specialty services they require.

An HSA can cover a wide range of special needs services including:
- psychologist services
- ABA/IBI therapy sessions
- private schooling tuition
- shadows
- tutors
- speech-language pathologists
- physiotherapist services

And an extensive list of other eligible expenses.

**How is an HSA funded?**

An HSA is funded through your place of employment where your salary will be broken up into two income streams. Consider the following simplistic example. Let’s say Mary Smith earns $100,000 per annum and she spends $18,000 a year on special needs services for her son. Her future earnings will now be amended to be $80,000 in salary (taxable income) and $20,000 (non-taxable income) that will flow into her HSA. Mary’s total compensation has not changed. Only the form has. The money from the HSA has flowed through to Mary tax free and can now be used to pay for all of her son’s health related expenses.

Note: The money from the HSA can be used to pay for her entire family’s health related expenses. Not just her son’s special needs requirements.

**Does my place of employment qualify?**

- **Self Employed and Incorporated** – Yes
- **Self Employed and Unincorporated** – Yes, but with limitations
- **Small-Medium Sized Business** – Company must agree to amend salary
- **Large Company** – Company must agree to amend salary

The HSA is available in all provinces except Quebec.

**How much can you contribute to an HSA?**

There is no maximum limit as to the amount an individual can contribute to an HSA. Generally though, when an individual opens up the HSA, he or she will have to estimate how much they think they will spend during the next 12 months. This amount cannot be amended until the contract policy year has expired, unless there is a life altering event.

**How it works**

Consider the following example to better understand how the Health Spending Account has helped many Ontario families afford the special needs services they need: Don and Mary Smith work full time. They have recently enrolled their child in a private school with special needs support. In addition, they also have a speech therapist that works with their child once a month, a private tutor that comes to the house every week and daily intensive ABA/IBI therapy sessions.

**Costs:**

- ABA/IBI $26,000
- Speech Therapy $6,000
- Special Needs Tutoring $5,000
- Private School Tuition $30,000

**TOTAL**: $67,000

**Using the Medical Tax Credit only (Without an HSA):**

- Gross income required: $95,374.29

**Using the Health Spending Account:**

- Gross income required: $76,152.78
  - (Cost of services plus admin. fees and taxes)
  
| Savings to an HSA Holder: | $19,221.47 (29%) |

The Health Spending Account holder will save nearly $20,000 and 29 percent on the costs associated with providing the essential services their special needs child requires. This new savings can now be used to purchase additional services should they be necessary.
What if the amount is over/under estimated?

Not a problem. If the annual amount is over estimated, then the amount of contributions in the following contract year would be reduced. Any unused amount is carried forward. If the annual amount is under estimated, then the contributions can be increased to recover the total expense. The ability to cover the previous year’s expense will not be lost.

However, no expense can be recovered if they occurred before the HSA was set up.

Understanding How the HSA Can Help You

Health Spending Accounts may be one of the least understood yet most significant deductions available on personal and corporate tax returns. With over 20 years of financial advisory experience, it is my belief that the Health Spending Account is the essential vehicle to help families afford and better manage the vital services their children require.

If you would like more information on Health Spending Accounts, or to determine if this financial vehicle would be of assistance in your situation, contact Rick Machtinger at 905 470-7788 ext. 242 or rick.machtinger@dfs.in.ca.

Rick Machtinger is a Certified Financial Planner with Desjardins Financial Security Independent Network. He graduated with his Bachelor of Business Administration from the Schulich School of Business at York University in 1983 and his Masters in Business Administration from the University of Windsor in 1984 where he specialized in Finance and Investment Management. Prior to joining DFSIN, Rick worked for Freedom 55 Financial. Rick has been advising a wide range of clients since 1991.

Reference: CRA Guidelines Interpretation Bulletin IT-85R2

Learning to Get Along

PART 2: INCREASING SOCIAL SKILLS AND PEER INTERACTIONS IN CHILDREN WITH AUTISM

by Laura Dignard, MADS, BCBA
Program Manager and Senior Therapist,
AlphaBee IBI and ABA Programs

CHILDREN WITH AUTISM SPECTRUM DISORDER (ASD) often exhibit impairments in their social skills development. They may have limited social interactions, have difficulty initiating and responding to social interactions, prefer to isolate themselves or interact with adults rather than peers, and/or have weak motivation for social interactions. For many children with ASD, social skills must be taught directly: simply having the child exposed to peers is often not sufficient for the child to learn social skills. Specific social skills targets should be a part of any intervention or education plan. How do we teach social skills to children with ASD? This article will review some strategies for assessing and teaching social skills in children with ASD.
Before selecting what skills to teach, it is important to assess where the child is at developmentally in terms of his/her current social skills repertoire. It can be helpful to look at how social skills develop in typical children. Understanding how typical children play and interact can help determine what to teach the child with ASD. It is important to keep in mind, that social skills development, like any skill, can be delayed in a variety of ways, so the assessment used should be able to identify these. For example, a child could have weak prerequisite language skills. If a child is not able to communicate his/her wants and needs, answer simple questions or follow instructions with adults it is unlikely that they will be able to interact with peers in a meaningful way. Teaching language and other prerequisite skills may be a priority before social skills becomes a major focus. Some children may have more advanced language skills but have weak motivation to interact with peers and prefer to be on their own. For these children, initial goals may be to pair peers and peer interactions with reinforcement. Other children seem to want to interact with their peers but do not have the skills to do so effectively. In any case, the goal of the assessment is to determine where the child’s social skills are developmentally, to then guide the selection of teaching targets.

Teaching social skills can be complicated. There are many different aspects to social behaviour, including nonverbal behaviours (e.g., body language, proximity, facial expression and eye contact), verbal behaviours (what someone says), and listener behaviours (listening to what someone else is saying). The rules involved in social behaviour are often complex, vague and continuously changing. Many social skills, especially advanced ones, involve complex skills (e.g., attending and listening, asking and answering questions, staying on topic, monitoring your own facial expressions, tone of voice, proximity, emotional regulation and coping skills, etc.). In addition, peers are often not as reinforcing as adults and they compete for adult attention and for turns; they often do not share or take turns or wait. Peers do not respond as quickly and clearly as adults do, they are not very skilled at reading facial expressions and body language, they do not wait for slow responses or poor articulation, and they may have deficits in language and social skills similar to the child with ASD.

Social skills can be taught to early, intermediate and advanced learners. The specific skills taught and how they are taught may vary, however. For example, early social skills may largely be with adults and require adult prompting. Eventually the goal is to have the child interacting with peers with minimal adult support. When it is appropriate to have peers involved, it is a good idea to start with peers who are able to model appropriate social and language skills.

AlphaBee provides Applied Behaviour Analysis (ABA) based programs to children and youth with Autism. AlphaBee has established itself as an exceptional program with a highly skilled clinical team, dedicated to assisting each child with reaching his or her potential. AlphaBee offers a range of ABA based services such as Intensive Behavioural Intervention (IBI), behaviour assessment and consultation, social skills training, and others. AlphaBee families are funded through the Direct Funding Option (DFO) or through private means. AlphaBee’s programs take a verbal behaviour approach to assessment and treatment and are individually tailored to meet the needs of our clients. Programs may include teaching language and communication, play and social, personal care and daily living, academic, and fine and gross motor skills as well as reducing challenging behaviours. We value input from parents in the selection of program goals and provide parents with training on how to implement strategies themselves. Our team is committed to improving the quality of life for children and their families.

AlphaBee’s sister company, wm+a is a leading provider of ABA and evidence based supports dedicated to making everyday a better day for the clients, families, and communities we serve. From Respite to Crisis Management, wm+a provides direct 1:1 or group support and teaching to children, youth, and adults with ASD in the home, school/day program, hospital, or community program. With a strong foundation in ABA, a skilled management and frontline team, we are technologically advanced, quick to respond to service requests, effective in delivery and committed to continued learning and growth within the support community.

wm+a and AlphaBee collaborate on joint projects: training programs for wm+a associates, community agencies and parents; children’s social skills groups; Next Steps — post IBI ABA-based tutoring; and more.

With two main office locations and IBI treatment centres in Toronto and Hamilton, and a team of over 350 frontline professionals, our services are available in the GTA, York and Simcoe, Durham, Peel, Hamilton/Niagara and Central West regions. Visit our website www.wmanda.com or call us to discuss how we can be of support to your family.

Dunya Marijan-Winterson, CEO wm+a and AlphaBee
Brenda Scott, Director of Services and Programs
Laura Dignard, AlphaBee Program Manager
416-367-5968 • 905-524-3843 • www.wmanda.com • www.alphabee.com
Peers should be generally cooperative with adults and be able to follow adult prompts. It may also be a good idea to talk to the peer(s) about what you would like them to do. For example, you may role-play or pre-teach the peer certain responses. When training starts, both the child with ASD and the peer(s) should be reinforced for interacting with each other to promote continued interactions in the future.

For a child with early language and social skills, initial goals may include pairing the peer with reinforcement and requesting from the peer. The primary goal of these early interactions is to teach the child with ASD that there is a benefit to peer interaction. Peers can be reinforcing.

Once the child is approaching and staying near the peer, additional targets may include parallel play, imitating the peer and following simple instructions from the peer. These can be taught in the context of simple and fun activities. Additional goals at this early stage may also include simple turn taking (e.g., Mr Potato head, puzzles, pushing cars down a ramp, going through a tunnel, etc.). Be careful not to teach sharing and turn taking too early though. One of the earliest and possibly most important goals is to pair the peer with reinforcement and not that playing with peers means having to give up all your favourite things.

For intermediate learners, the social skills curriculum may include goals such as requesting attention from peers, following play led by peers, initiating play with peers, playing pretend or interactive games, and so on. Target goals for advanced learners may include asking peers questions and answering questions from peers, talking to peers, telling jokes, dealing with conflicts or arguments, recognizing and coping with emotions in social situations, and so on. The list of skills to teach may seem endless and to some extent, social skills training never ends. What is important to keep in mind, is to select skills appropriate for the child’s developmental level and to gradually increase the difficulty and demands.

What follows are some general tips and strategies to promote social skills and interactions with peers. First, it is often necessary, especially early on, to set up and create opportunities for social interactions. Adults may have to instruct children to interact with their peers and vice versa, and prompt children and peers during their interactions. Activities should be selected that are reinforcing for the child with ASD and the peer, require proximity, interaction and cooperation.

Second, select peers that are willing to help, that follow instructions, attend to adults and are generally cooperative. Talk to the peer ahead of time about what you would like them to do or say and how to respond. Make sure to reinforce the peer for participating. Initially start with a select few peers and gradually increase the number of peers the child can interact with.

Third, pair the peer(s) with reinforcement. For many children with ASD, peers are associated with reduced adult attention and the loss of toys. For more advanced children we do need to teach them to tolerate these things, but for the early learner, we want to start by teaching them that peers are fun and there is a benefit to interacting with them.

Finally, there are many different curriculums available for assessing and teaching social skills that break down skills and provide teaching strategies and steps. It is a good idea to use a social skills curriculum because social skills involves many skills and can get complex at higher levels. Some sample curriculums include Making a Difference (Ed. Maurice, Green, & Foxx, 2001), Navigating the Social World (McAfee, 2002), Do-Watch-Listen-Say (Quill, 2000) and Crafting Connections (Taubman, Leaf, & McEachin, 2011).

Teaching social skills can seem complicated. Social behaviour itself is complicated. Using a structured assessment and programming tool can help to guide a child’s curriculum and make teaching more efficient and effective.

feature SPECIAL ADVERTISEMENT
Kidnastics

TURNING THE ROUGH AND TUMBLE OF LIFE WITH ASD INTO A FUN THING

by Rachele Hosten

Sometimes the littlest gains are the sweetest.

Rachele Hosten combines coaching skills with custom interdisciplinary interventions to meet the needs of special children in the gymnastic setting. A competitive coach, focused for over 20 years on producing athletes, by coincidence, Rachele was asked to provide private classes for a boy referred to gymnastics activity by his physician. The initial success with the first client led to referrals, and a new service developed, designing custom accommodations and programs via collaborative partnerships to support children with a special need.

I NEVER ADVERTISED for clients. Ever. At first, I was “the strict coach.” “Difficult” children seemed to benefit from my firm guidelines, so many of my students were ones who had been redirected to me when other class placements had failed. I noticed many of these children had common behaviours. I was curious to figure out effective strategies for this population of mostly boys that could not function in a regular class.

With no peers to share experiences with, I learned as I went; I was friendly and flexible in my approach and did whatever it took to get these children playing. If a child was too stressed or lost to walk to the trampoline, I carried him. (I called it “executive support.”) I was proactive, kept it simple and tried to establish positive entry and exit rituals immediately. I used verbal, physical and other prompts, and made sure I was the Alpha in most control battles. (I had built-in leverage as the gatekeeper to the trampoline and foam pit: First stretch, then tramp was the rule.) I added artistic, musical and literary components to standard and custom-modified gymnastics curricula.

I loved figuring out the puzzle of each child. My identity changed. I had become a special needs coach, and I had developed a successful program for children with ASD.

Now, I run Kidnastics Inc., a small company that focuses on making a difference for children with special needs and to support family and community agencies with the logistics of meaningful inclusion. To share information, strategies and stories, Kidnastics Inc. offers practical clinics for clubs, schools and an array of practitioners.
I developed a unique special-needs, interdisciplinary program based on the training models and level systems of Canada’s Long-Term Athlete Development Program (LTAD). I consider Ontario’s High-Five learning concepts, but I cannot follow all of them. To these I have added specific, evidence-based best practices: ABA and errorless learning, Social Skills as taught at The Geneva Centre for Autism, and onsite sensory profiling and accommodations. When recommendations are contradictory I consult parents and advisors. Keeping updated about ASD is a priority so I to attend conferences. It was at one of these, The Geneva Centre for Autism’s International Symposium in October, 2012 that I had my “aha!” moment. Dr. Tony Atwood, a world-renowned autism expert, recommended trampoline and gymnastics activity for children with ASD. I went up to speak to him after his speech and he penned a note of support. It was encouraging! At the same conference, Michelle Garcia Winner spoke about Social Thinking, and at some point joint attention was mentioned, the “reading intentions of others and paying attention to others and the environment” (Jones and Carr, 2004). As a former coach of athletes, I understood that a missed stage of movement could be problematic later on, but I had not realized there was a name for this hallmark of the Kidnastics Inc. program. I was so excited I flew to Orlando the following December to a Social Thinking Conference featuring the ILAUGH model. There, it became clear to me that the type of interdisciplinary gymnastics activity that I do was setting a foundation of a kind I never expected. I had goose bumps. In the gym, I foster joint attention and have come to realize in hindsight that it is is one of the first social stages. I focus on building foundations, both physical and social.

So, what does this all mean for the children I work with? Well, working in the gym is fun! The physical environment offers a wide selection of stimuli, and a child is sure to find something engaging and also develop tolerance for less pleasing stimuli. I have unique opportunities for eye contact; for example, while I’m bouncing a child who is lying on his back on a trampoline and he is fidgeting, we share an action song or story face to face. I observe for any sign of intention, focus on it, and make the dream come true by supporting the manifestation into action. I model and amplify responses; I observe the children’s subtle communication clues and follow up. If they like shiny things, I provide shiny things and lure them. (I’m the “candy” lady.) Once I have a rapport, I can use it to leverage their attention and their intention. An inside joke is the bonding base for future coach and athlete rapport.

Sometimes the littlest gains are the sweetest. I coach nine Severely Impaired Communicators who are non-verbal to semi-verbal. For some participants, a parent and/or PSW are required for smoother, safer transitions (bolting is one of many issues). These non-verbal children are amazing to work with. The group includes a 15-year-old boy I’ve coached since he was six – poetry in motion and hands-down the highest jumper on the trampoline. Two busy nine-year-old boys experienced improved speech in the gym, and a four-year-old stopped screaming and blossomed into a laughing boy who walks and plays.

One cannot predict, so I don’t worry. My strategy is to work a program consistently, have fun, and be patient. Development occurs eventually. While there is much to be studied, proven or
debunked, I do not think it is ridiculous to consider the merits of gymnastic participation, specifically for the ASD-affected child, as an adjunct to interventions. A handful of children with ASD can manage a typical program, but most benefit from a program with accommodations. Gymnastics is a gateway sport, as physical skills do transfer. Making friends and sharing peer experiences are important to any child, and the gym facilitates these for children on the spectrum lacking natural friendship skills. (Sadly, many children are lonely; one of my greatest challenges is organizing peer sessions in cases where parents cannot commit to joint schedules.)

Motivated by crisis management, I invented what I do, before “inclusion” and “Aspergers” were household terms. Please note that I’m an independent artistic gymnastics coach – not a therapist – who works in partnership with individuals or teams. In the gym, we do gymnastics for the love of it, not for health. Gymnastics fulfill our passion. As in any sport, participants rise to the challenges that participation demands. We engage office staff with friendly greetings, clap for athletes that impress us, and say hello to other coaches in the gym. If a child gets stressed, we finish the task at hand, use targeted strategies to cope, and redirect attention. Belief in the right of every child to participate and reach their full potential forced me to learn, develop new skills and pursue measurable success for the special children in the gym. From preparing competitors, I’ve moved to preparing players. And I love it!

Kidnastics Inc.
416-737-1255
rachele.hosten@gmail.com
www.kidnastics.com

Scholarships

TRAINING A NEW GENERATION FOR THE BENEFIT OF THE ASD COMMUNITY

by Doris Barkley, Autism Ontario Board of Directors, Scholarship Committee

THANK YOU TO THE CHAPTERS that made donations to the Scholarship Fund. Funds raised this fiscal year (April, 2013 – March, 2014) will pay for the scholarships that were given out in June, 2013. We encourage all chapters to contribute in any amount you are able.

Eleanor Ritchie Post-Secondary Education Scholarship

We are very excited and pleased to have received 45 applications for the Eleanor Ritchie Post-Secondary Education Scholarship for students with ASD. This award is named after Eleanor Ritchie, a long-standing member of Autism Ontario, in recognition of her dedication and support for individuals with ASD. The annual award is in recognition of the achievements of students with ASD who are enrolled in a post-secondary education program. Each award consists of $1,000 towards their first year tuition fee.
This year we are very pleased to be able to award four students. Names were picked randomly using an excel computer program.

**Mark Athanasiadis** from Markham will be attending York University in a four-year Bachelor of Music program. Mark has a passion for music. He plays the drums and percussion in many bands along with singing in an AcaPELLA group and a concert choir. He also plays piano and ukulele. He wishes to become a music teacher in a high school. He states “performing music really makes me happy and I feel good whenever I’m in a happy environment.”

**Alyssa Ferguson** from Cambridge will attend Conestoga College in the Broadcast-Radio Program. Alyssa is looking at a career as a radio broadcaster and has a keen interest in music.

**Mitchell David Helm** of Lucknow will attend Conestoga Polytechnic in the Technology Foundations Program. He states that it is a small campus and they have a very good disability department, which helps with projects, studying and exams. This is the first step in his dream of becoming a mechanical engineer, which is a four-year degree.

**Shayne Campbell** from Leamington will attend the University of Windsor for a BA Honours program, Communication, Media and Film. His goal is to be involved in the industry of filmmaking, acting, radio broadcasting or teaching. We were very pleased that Mitchell Helm and his parents were able to join us for the presentation prior to the AGM on June 8.

Congratulations to all the recipients of this year’s Eleanor Ritchie Scholarship.

**The Jeanette Holden Post-Secondary Entrance Scholarship to Siblings of Individuals with an ASD**

Autism Ontario is also pleased to offer this award, named after Dr. Jeanette Holden, a sibling of an individual with ASD, in recognition of her dedication to ASD research and her contributions to unravelling the mystery of ASD. Dr. Holden, who passed away of cancer in February, 2012 was a dear friend to so many at Autism Ontario.

This annual award is given in recognition of the role and contributions of siblings to the welfare of individuals with ASD. Each award consists of $1,000 towards the first year tuition fee. This year we had 23 applications for this scholarship. Each applicant submitted an essay, their grades for the last two years of high school, letters of recommendation and letter of acceptance to a college or university for the fall. We are very pleased to present this award to two students.

**Janet Kim** attended Richmond Hill High School and has an older brother Jimmy with Aspergers. She acknowledges that comprehending her brother’s wants and needs is often difficult. His coping daily with frustration, anger and misunderstanding helps her admire his bravery and courage. Janet decided at a young age that she would dedicate her career to improving the lives of those with autism. She volunteered as a counsellor at a special needs camp, which her brother attended, which taught her that each camper had different needs and requires different approaches. For the past several years, Janet volunteered at Mackenzie Health Hospital in various capacities with increased responsibility. She notes that regardless of the age, gender or illness, she is able to connect and aid those around her, which was very satisfying and meaningful. Though Jimmy is unable to speak, they love to see him laugh and enjoy the fresh air and exercise during the family’s daily walks with their dog. Janet says that his beautiful smile keeps the family together. Janet shares in personal care for her brother by brushing his teeth, helping him eat and caring for him when their parents are out. Her brother sometimes rips her homework or ruins her belongings, but rather than becoming upset with him, she has learned to be more careful and will often study at the library, as her brother loves loud music. Janet says she is blessed to have her family and tries her best at everything she does. She makes time for personal growth and enjoyment. Janet was the first chair oboist in the school’s senior band, is an avid debater on her school’s debate team and her average for 14 Grade 11 and 12 courses was 97.4 percent.

In her reference letter from Benjamin Lee, he states “I believe that her loving and understanding personality comes from observing her brother – throughout the years, she has learned to view things in different perspectives. She is a mature and kind student who truly loves her family.”

Her brother’s diagnosis of autism has not only influenced her life but also her future career goals.

Janet and her parents were present at the June 8 AGM and said the following when she accepted her scholarship.

“Thank you so much for this scholarship. I truly appreciate everyone coming out to support students and adults that want to make a contribution to those with ASD. Next year, I will be attending McMaster University for their Bachelor of Health Sciences program. I hope to become a physician and specialize in neurology, where I can contribute to ASD research as well as work with mentally disabled patients. It will be difficult, but I will do my very best to make a difference. Thank you so much for your support and this wonderful organization.”

**Kayla Peel** lives in Brooklin, north of Lucknow.
of Whitby. Kayla will attend Trent University in Peterborough in the fall where she will be enrolled in the Honours Arts Program in Psychology. She hopes to continue after her undergraduate degree with a Master of Health Sciences in Speech Language Pathology at U of T. Her sister Christy (who has autism) received treatment from a speech language pathologist starting at a young age. Kayla’s dream is to work with children who have autism or other special needs, in order to help them learn to better communicate their thoughts and feelings. Being close in age, Kayla and Christy are very close, have faced many times of laughter and tears, ultimately surviving the teenage ups and downs together. Kayla has been an advocate and acknowledges that she will support her sister throughout her life. Kayla says that Christy deserves to be treated with respect and dignity. Kayla supports others with similar challenges by participating in annual “Walk Now” for Autism Speaks events and has been a participant with the Autism Research Unit at Sick Kids. In 2008, Kayla spoke at the Genetics of Autism Conference at Sick Kids about the challenges and victories that come with having a sibling who has autism.

Kayla has volunteered at Calvary Baptist Church through their Adventure Day Camp as a personal worker for children who have autism, Down syndrome, cerebral palsy, ADHD and FAS. This community-focused initiative reaches out to kids who are not able to afford summer camp. The camp director, Rebekah McIntee, noted that Kayla truly made a difference in the lives of kids with special needs. She was an integral part of the team through her genuine character, initiative and positive attitude. She brought forward innovative ideas from her experience with a sibling who has ASD and successfully applied them in the community environment. She has been a great help and resource to other staff.

In August, 2012 Kayla spent three weeks in Zambia, Africa working with children who had been abandoned due to their physical or cognitive disabilities. Kayla’s time with these children confirmed her desire to work towards being an SLP.

During her spare periods at school, Kayla helps in the developmentally handicapped classroom. She averaged 95 percent in her Grade 11 and 12 courses and completed her Grade 8 Royal Conservatory of Music in Piano in elementary school. She has given various speeches to classes at her school on autism to create more awareness.

Kayla credits her sister Christy for helping to shape the person she is today, bringing encouragement, support and love and for bringing a special dynamic to their family.

We are pleased that Kayla and her parents were also present for the presentation. Congratulations Janet and Kayla on being selected by Autism Ontario as recipients of this year’s Jeanette Holden Entrance Scholarship.

Now, more than ever, this old adage is true. The stats on the rise of autism are alarming, but awareness of autism is also on the rise. Parents are no longer alone. Educators, politicians, healthcare professionals and the community have an opportunity and an obligation to help children to achieve their full potential and find their place in society. We’re here to support, encourage and enable.

*We are pleased that Kayla and her parents were also present for the presentation. Congratulations Janet and Kayla on being selected by Autism Ontario as recipients of this year’s Jeanette Holden Entrance Scholarship.*

**It takes a village to raise a child.**

Now, more than ever, this old adage is true. The stats on the rise of autism are alarming, but awareness of autism is also on the rise. Parents are no longer alone. Educators, politicians, healthcare professionals and the community have an opportunity and an obligation to help children to achieve their full potential and find their place in society. We’re here to support, encourage and enable.

*Autism Matters* is a publication of Autism Ontario. For $25, “Friends of Autism Ontario” can learn about autism all year round with a one-year subscription (four issues). You’ll receive the most recent issue when you subscribe. Please provide full mailing information and a cheque payable to:

**Autism Ontario**
1179 King St. W., Suite 004
Toronto, ON M6K 3C5

Members of Autism Ontario automatically receive a copy.

Visit our website: www.autismontario.com to view back issues of our magazine.
Diversity in Ontario’s Youth and Adults with Autism Spectrum Disorders: 
Finding and Keeping Employment

No. 61, April 2013
By: Claudia Accardi, MSW, RSW & Sarah Duhaime, MSW, RSW, The Redpath Centre

This article summarizes some of the information contained in the recent report entitled Diversity in Ontario’s Youth and Adults with Autism Spectrum Disorders: Complex Needs in Unprepared Systems.

Finding and keeping meaningful employment is often a challenge for youth and adults with Autism Spectrum Disorder (ASD). Underemployment is also a concern, as many individuals are employed in positions that require performance significantly below their skills, knowledge, or training. Being employed and self-sufficient financially contributes to improved self-esteem, increased independence and reduces reliance on income support programs.

The research on employment and services in Canada for those living with ASD is sparse. During our recent Ontario study of 480 youth (16+) and adults living with ASD (Stoddart et al., 2013), families and individuals with ASD shared their employment status and their experiences in the workplace. Only 13.9% of the participants 20 years and older relied on full-time employment as their primary source of income, while 6.1% relied on part-time employment. Also, the majority of people (58.2%) depended on Ontario Disability Income Supports (ODSP) as their primary source of income.

In the same study, 30% of those employed were found to be working in “sales and service occupations”. This finding reflects that although individuals with ASD may not naturally have the “soft skills” to interact and function in these types of environments, these service-oriented entry-level positions are often the occupations available. “Business, finance and administration” were reported to be the primary employment fields for 15.1% of the participants.

Other studies have been conducted in the area of ASD and employment, however more research is needed on ASD-specific vocational interventions. Mawhood and Howlin (1999) in the UK studied the outcome of an ASD vocational intervention compared to a control group which did not receive ASD specific employment supports, and concluded that those in the ASD-specific group had higher salaries, worked longer, and reported more satisfaction than the control group.

A further argument on the benefits of ASD-specific vocational programs is derived from Cimera and Burgess (2011) in their review of the monetary benefits/costs of adults with ASD working in their communities in the US. This study concluded that across all states, those individuals participating in vocational programs most frequently were at a monetary benefit when considering programming costs and training.

Whether we are in the role of service providers, parents, or individuals with an ASD, our challenge is not only to increase the numbers of youth and adults with ASD who are employed, but also to ensure that they achieve long-lasting meaningful employment.

Challenges to Accessing Employment Faced By Youth and Adults With ASD:

- Preparing for and attending an interview—difficulties managing anxiety, reading social cues, communicating appropriate information
- Social interactions with colleagues, organizational skills and sensory challenges
- The work activities required might not be perceived as challenging, rewarding or meaningful
JOIN TEAM AUTISM ONTARIO as we celebrate our 40th Anniversary as the province’s largest collective voice, representing more than 100,000 families who deal with an Autism Spectrum Disorder (ASD).

About Autism Ontario
Autism Ontario is a not-for-profit charitable organization founded in 1973 and is a strong voice for individuals with autism.

We reach more than 50,000 families annually, through our provincial office and 24 chapters located around the province, largely run by parents and volunteers. We provide services and supports in local communities such as camp programs, social learning opportunities, respite, parent support groups, as well as funding evidence-based research, education for parents and professionals. We continually strive to increase public awareness of Autism Spectrum Disorder (ASD), and advocate within municipal, provincial and federal government ministries for what is needed to support individuals and their families throughout their lifetime.

Your support will help us continue the work we do, and the support so necessary for thousands of families.

Join our team. Walk for those who cannot, be the voice for those who cannot speak, and help families who live with the reality of autism each day. This is our first year of participating in the Scotiabank Charity Challenge and our goal is to raise $25,000.


How can you help?
• Join our team and participate in the marathon, half marathon, or the 5k race.
• Sponsor an individual participant or Team Autism Ontario.
• Bring along your friends, family and neighbours. This fun-filled event is a great way for the entire family, young and old, to join together in giving back to our community.
• Make an online donation to our cause at www.autismontario.com. Electronic tax receipts will be issued for donations of $20 or more.

Full marathon, half marathon or 5K – all runners and walkers on Team Autism Ontario must commit to raising $250 or more. If you raise more than $500, we will reimburse you for half of your registration fee; raise more than $750 and we will reimburse your full registration fee.

Contact Monica Richardson at monicarichardson@rogers.com for more details.
• One in 94 children are being diagnosed with autism in Canada, and it is three times more prevalent in boys.
• Autism affects communication, social interactions, cognition and behaviour.
• Children with autism grow up to be youth and adults with autism.
• A lifetime of support is needed, and there is no cure.
YOU MAY RECALL that Autism Matters ran an article in fall 2012 entitled, “I Have Autism and I Need Your Help.” The article was two-fold: the preface was written from my perspective, and my son Erik’s portion was a letter to his school administrators. In reaching out to school staff, Erik described what it is like to be taught in words when you think in pictures. It was a tough year for a child with autism.

Both Erik and I were overwhelmed and overjoyed by the response to the article – from parents, kids with ASD, brothers, sisters, grandparents, teachers, teaching support staff, principals and superintendents. Although the perspectives were quite different, the sentiment was the same: we learned something about the ASD perspective. Thank you!

Encouraged by our local Autism Ontario chapter, and supported by Autism Ontario provincially, we have decided to pick up where we left off and continue the mother-son collaboration. Erik and I envision a series of articles which would both enlighten parents and help their ASD children. Our idea follows the oxygen-mask model: parents employ the strategies first and then use techniques learned to support their children. Each article will start with the “I Have Autism and I Need Your Help” root followed by a help suffix, such as the article to follow, “I Have Autism and I Need Your Help: Cultivating a Positive Attitude.”

The series will be step by step and explicit, starting with broad considerations such as nurturing attitude, perspective and self esteem and then working toward specific such as self-regulation, transitions, traditions, change, time management, organization, self-advocacy, and so forth. Our collaboration will emphasize and celebrate the relationship between child and parent. We are, after all, our child’s first and life-long teacher. In addition to anecdotes and specific teaching points directed toward parents, the series will also present each topic from the perspective of autism. Was the teaching of each topic and the strategies used helpful? Erik’s input will explore how each strategy and topic was helpful.

In terms of layout, Erik’s perspective will be indicated by a thumbnail photo and a change in font so that it is clear when he is speaking. My perspective will also be represented by a thumbnail photo to signal that the words are mine. In order to support the ideas visually, Erik has offered to animate key points with art windows. I like to think of these as glimpses into his mind.

Given the recent Redpath Centre study and report, “Diversity in Ontario’s Youth and Adults with Autism Spectrum Disorders: Complex Needs in Unprepared Systems” (February 2013), it is clear that we need to look ahead to where adults with ASD are running into challenges and use this as a basis – the curriculum – for our children with ASD. We need to provide our ASD children with the skills they need, starting at a very young age, and we need to build upon these skills daily. This is the idea behind the series. As one speaker so eloquently worded it, we need to “look ahead to what counts” (Barbara Bloomfield, MA CCC-SLP “Looking Ahead to What Counts,” Halifax, 2012).

Erik and I hope that our thoughts and experiences will serve as a possible springboard for your own autism journey. We believe that our story is also yours; we are all in this together. A favourite thought to share en route? “If you are blown off course, just change your destination” (Danna Faulds: Turn Your World Red).
I Have Autism and I Need Your Help: Cultivating a Positive Attitude

CONTINUE IS THE POWER AND OTHER GUIDING LIGHTS

by Teresa and Erik Hedley

Continue is the Power.
“It’s what it means to be Japanese,” she told me, a shy smile growing on her lips. “We never give up.”
It’s also what it means when you have a child with autism.

BACKTRACK TO JAPAN, 1988. I was teaching English in a suburb of Tokyo. If I rolled my chair out into the hall and positioned myself just right, I could barely make out Mount Fuji in the distance. Here I was in Japan, and I was about to be handed a slip of cardboard that would forever change my perspective. It was, in fact, foreshadowing, but I didn’t know it back then.

Keiko Ishii, a Japanese junior high school English teacher, arrived a few minutes late. Brushing the rain off her jacket, she settled in at the table. This was a private lesson—just the two of us here to tackle English conversation for the next hour. She often came with small offerings, and tonight was no exception. She pulled a flat package out of her handbag and slowly unwrapped it. It was an art form of some sort, a five inch by five inch square of calligraphy.

“I painted it for you,” she said, leaning in and lightly touching her nose to emphasize the I. “It’s what it means to be Japanese. Guess!”

“Hmm...organized? Hardworking?” She looked hopeful. “Perseverance?”

“Yes! Yes...in Japanese we say, ‘Continue is the Power.’”

I nodded and felt her pride. What I could not know at the time was just how powerful those four words would become for me. Continue is the Power.

It is synonymous with parenting a child with autism. It is the fuel I draw upon each day. It has become my creed.

My Spark. My Springboard.
Fast forward 17 years. I have a six-year-old child diagnosed with autism. My days are filled with mulling over puzzling behaviour... investigating therapies... making goals... making plans... lining up play dates... searching out social skills providers... seeking the advice of OTs, SLPs and psychologists... making sense of specialist reports... booking appointments... attending appointments... composing e-mails to teachers, EAs, learning support staff and principals... signing up for workshops and conferences... attending workshops and conferences... searching for information... reading articles... reading books... reading blogs... attending support groups... gathering information... gathering strength... gathering steam... learning about autism... teaching
to Erik, I wear two more autism hats now. One involves meeting with parents of children diagnosed with autism. My job is to teach them about autism: I help them to step into their children’s shoes. After all, to catch a fish, you have to think like a fish. I help them understand their child’s perspective. I provide them a roadmap of services, resources, home support strategies, strategies to help their child in the community, action plans to deal with specific behaviours and advice and resources to help negotiate the school system. It is a full platter. In designing this road map, I understood that in addition to insight, information and implementation strategies, I needed to provide the most elusive — the inspiration to carry on day after day. How does one teach that? How does one impart the strength to gather steam and tackle the list, day in, day out? I decided that I would bookend the parent resource package with inspiration. On the front is the calligraphy Continue is the Power. On the back cover is the poem Impossible Garden. Impossible is all in the hands of the beholder. Impossible also means “I’m possible.” It’s a matter of choice, as are most things in life.

The Power of Guiding Lights

These two poems have helped me to tackle many autism bad weather days. If these guiding lights worked for me, why not others? This led me to ponder my support strategies for Erik. If it worked for me, why not for Erik? What’s good for autism is good for the neurotypical population and vice versa, right? I figured if I drew so heavily upon guiding lights to fuel my determination, then Erik could probably also use some positive fuel, too. My son needed a frame for his thoughts and perceptions.

A Little Thing That Makes a Big Difference

We are always told how important a positive attitude is — you know, “a little thing that makes a big difference?” Yet, when you think of it, we are seldom told — really taught — how to cultivate a positive personality. In a world that is often confusing and loud and rapid-fire, it must be very difficult for children with ASD to be upbeat. I felt that if anyone needed a positive filter, it is kids with autism. It was time to share my secret supports with my son.

I started with the calligraphy. I made a copy for Erik and for my two other children, too, and tacked the laminated squares to their bedroom bulletin boards. I explained the poem and the power it held for me. As life’s challenges presented themselves, we applied the Continue is the Power frame... and later the “You Never Know What’s Good and What’s Bad” frame, and so forth. I went first. I modelled the approach and the application of these wise words to life’s challenges.

Now I sit back and reap the rewards. My children are finding the positive in the tough times; they are offering up life’s lessons for me because they have been taught how to do this. It works
for parents mentoring children, and it seems to work especially well for those of us supporting children with autism. It works for neurotypical kids. And children with autism? I daresay it works for them, too. Let’s ask Erik.

First, though, a quick aside. Two points. **One**, there are many ways to cultivate a positive attitude; building and drawing upon a personal collection of guiding lights is just one. **Two**, why is it important to cultivate a positive perspective? As a caregiver, it is a source of strength. It is the power it takes to tick off the lists, day in, day out. As a child, it lays the foundation for all interactions and all forms of growth and therapy. If you are positive and open-minded, you are more likely to benefit from self-improvement strategies. Also, you are nicer to be around. It takes a small village to support and nurture a child with autism. It really helps when the villagers are happy because they truly like being with you. If you learn to frame things in a positive manner, then people will want to be with you. They’ll want to work hard for you. It makes perfect sense.

Now, to Erik. Aside from *Continue is the Power*, it would be helpful to know what keeps him glued together and what helps him maintain a positive attitude. What are his personal guiding lights, indeed, his **rules for life**?

**References:**

1. Continue is the Power: Given to me by teacher and artist, Keiko Ishii, Tokyo, Japan, 1989.
2. Impossible Garden: Given to me by Japanese student, Yuko Mitsunari, Vancouver, Canada, 1993.
3. *It Could Have Been Worse*: A. H. Benjamin; tvstechtips.edublogs.org
4. Cartoon Artwork by Erik Hedley, 2013

---

**Erik’s Rules for Life**

**“It’ll all work out.”** This is what my mom says to me when I have a lot of homework to do. I like when she says this because it makes me less worried and stressed about it. I feel like it’s going to be more of a team effort. I don’t have to handle it all on my own.

**“There’s no rush. We’ll all get to the finish line.”** I like this one because it shows that everyone has their own strategies for getting to the finish line. For example, I study for exams about a week in advance to get prepared. If I didn’t do this, I would feel worried about the exam and that I might run out of time to get ready. I take my time and this works for me.

**“You’ll be happy later.”** Normally when we’re taking pictures on vacation, I don’t really want to take the time to do this, but I say to myself, “You’ll be happy later.” And I always am. Otherwise, you forget all about the adventure, and the memory gets completely erased from your mind. For instance, when we go to the cottage in the summer, I really like looking at the pictures later on when we get home. I think to myself, “I’m glad we did this.”

**“You never know what’s good and what’s bad.”** I use this one a lot. Sometimes at school, instructions are only given in a spoken form and that makes me feel nervous because I can’t remember what teachers are saying. This seems to be a bad situation at first, but when I really think about it, it helps me in the future. This is because I am forced to ask questions and be a self-advocate. It isn’t easy but it’s good practice. You never know what’s good and what’s bad.

**“It could have been worse.”** This is the title of one of my favourite books from my childhood. It’s about a mouse that gets into all sorts of trouble and he thinks each thing that happens to him is the worst...but his mother always explains to him that it could have been much worse. I use this title to think about things in a more positive way. Everything that happens to me could have been even worse. Everything is relative in life. So I try to make a plan and some goals to make things better.

**“Erik will surprise you.”** This one is my favourite. It’s what my poppa said to my mom about me. This tells me that Poppa saw my talents and my abilities. He believed in me and he wanted other people to believe in me, too. I like the way this one makes me feel.

---

Continue is the Power. After all, it’s not so much what happens to us, but what we do about it that matters most. Plant all of your impossible gardens and see what blooms.

Up Next: I Have Autism and I Need Your Help: Celebrating My Perspective.
It’s SUPER-MAX to the rescue!

HERE HE COMES, WITH A JAUNTY WAVE AND A TIP OF HIS CAP – MY SON, POLITENESSMAN.

“THANK YOU, DADDY,” for the delicious dessert,” says four-year-old Max, striding into the kitchen with a cheery smile. “That Mr. Fudgee-O cookie tasted just the way I like it.”

“You’re welcome, my good man!” I respond with exaggerated enthusiasm. “And top of the day to you.”

I can’t help but smile. For Max, who has autism, has hit a particular phase in his development I find hard to not embrace wholeheartedly: he’s turned into a 1950s TV character, somewhere between Ozzie Nelson and Wally Cleaver, with a touch of Mr. Peepers.

“Thank you for the delicious vitamin, Daddy!... Thank you for making me such a delicious dinner, Mommy!... Thanks, Sammy (younger brother) for letting me borrow your plastic toy food!”

Eighteen months after Max was diagnosed with autism – a complex brain disorder that affects more kids than diabetes, AIDS, cancer, cerebral palsy, cystic fibrosis, muscular dystrophy and Down Syndrome combined – I’ve gleaned enough insight from therapy sessions and resource books to understand the broad parameters of what makes him tick.

In his world, everything – and I mean everything – provokes anxiety: bright lights, loud noises, changes in routine, people who can’t read his mind, the elimination of the Spice Girls’ Wannabe from the Rogers On Demand video rotation (which upset his Daddy as well).

If he thanks everyone profusely for everything, he figures, he’s sure to get a supportive response, which confirms for him that for every action, there is an equal and opposite reaction.

For kids like Max, this is an important concept.

So he’s walking around like Mr. Manners, thanking people for his cookie, dishing out compliments about delicious dinners, telling his Mom “your hair is soft and silky smooth” and noting, with wide-eyed sincerity, how generous it was of me to treat him to lunch in a local restaurant (“That pancake was delicious!”).

What can I say? It’s ridiculous, but oddly endearing.

It’s also misleading, because as with most kids with autism, things aren’t always so okily dokily with Max, an enigma wrapped inside a volcano, a sphinx with attitude.

“Sweet dreams,” he told me a few nights ago as I prepared to exit his bedroom after an exhausting ritual that included book reading, water drinking, back rubbing, monster evacuation (you, goblins – out of the closet!) and a few congratulatory high fives.

“Sweet dreams,” I respond.
“No,” says Max.
“What?” I say.
“NO!” shouts Max, outraged beyond belief. “NOOOOOO!”

Uh oh. I’ve given an incorrect response – that much is clear. And as I place one foot gingerly in the hallway, hoping to stealthily take my leave, his agitation reaches fever pitch.

“SWEEEEET DREAMS!” he screams, as if stung by a thousand hornets. “SWEEEEEEEET DREEEEEEAMS!”

I think for a minute, recalling a similar incident between Max and my wife, and change my farewell salutation from “sweet dreams” to a simple “thank you.”

Max looks shaken, but relieved. “You’re welcome,” he says, and turns over to go to sleep.

Whew. Autism isn’t a fun disorder. There are no hard and fast rules for navigating the treacherous emotional terrain when your child feels overwhelmed or – as we say in the special needs biz – dysregulated.

It doesn’t matter that Max is a sweet, lovable kid with a curious, probing intelligence.

Or that since he started junior kindergarten last fall, his developmental delays have been eclipsed by an aptitude for puzzle assembly, scaling snowbanks and singing the alphabet.

Or that, despite social communication deficits, he’s morphed into a capable older brother, offering toys, hugs and the occasional stern lecture (“Sammy, you need to calm down!”) when his imperantinent sib knocks down Max’s painstakingly constructed block towers.

The truth is, none of these things compensate for the lack of an emotional buffer that remains Max’s biggest challenge. In that regard, he’s like the box of chocolates in Forrest Gump: you never know what you’re going to get.

Cut to a few weeks ago, on a typical outing with both boys to the park. Sam wants to look at the outdoor wading pool – our comical habit all winter – to see if, despite the piles of snow and ice, it might be open for a quick dip.

Max – whose logical mind is not given to flights of fancy – wants to bypass this ridiculous detour and head directly to the playground, where ice slicks on the twirly slide shoot little boys off the bottom like an Al MacInnis slapshot.

Since there’s only one of me, tough decisions have to be made.

“Max, you need to come with Daddy,” I tell him as he hangs back a few dozen yards. “I already told Sam we could check out the wading pool.”

“I don’t want to go to the pool,” he announces, and I recognize the panic in his voice. “I want to go to the playground.”

If he thanks everyone profusely for everything, he figures, he’s sure to get a supportive response, which confirms for him that for every action, there is an equal and opposite reaction.

“Max,” I tell him again, aware that my other son needs to be respected as well. “You can’t go off by yourself, and we have to be fair to Sammy. Come with us, and then we’ll go to the playground.”

“No.” At this point he sits down, typical behaviour for a frustrated four-year-old: stubborn, intransigent, ticked off.

And then – like Bruce Banner transforming into the Hulk – the Autism Factor kicks in.

“I don’t want to go anywhere with you, Daddy,” he starts bellowing, visibly upset. “I don’t like you anymore! I don’t want you to be my Daddy! I want Mommy. MOMMEEEE!”

And, suddenly, he’s on the ground, kicking and screaming, hitting himself on the head – hard – as passersby wonder what the heck is going on.

“I’m not going ANYWHERE with you! I don’t love you anymore! I want Mommy! MOMMEEEE!”

And that’s it: annoyance, outrage, complete devastation. Six seconds is all it took.

So I pick him up – what can I do? – and do the stuff his therapists have recommended: hug him tightly, massage his arms and legs and speak gently, reassuringly. Sometimes it works, and sometimes, like now, it’s a lost cause. It has to play itself out.

“Ow, you’re hurting me! Ow! Ow! MOMMEEEE!”

Cut to a half-hour later, after a post-meltdown stint at the playground that proceeds happily, without incident.

The sun is setting, it’s -13 C, everyone is cold and tired, and as I wheezily pull the sled with both boys up the steep hill to our house, I suddenly notice that – dammit – the snow has run out.

It’s been a half kilometre of smooth gliding to this point, but due to some diligent shovelling, the sidewalk ahead is as unsurpassable as the Sahara in a sandstorm.

“Looks like we’ll have to get out and walk,” I inform Max and Sam, aware I’m actively courting mutiny. And then I notice Sammy slumped over the front of the sled, fast asleep.

“Sammy? Uh oh. Sammy?”

Now I know Sam. He’s a trooper, but even if I succeed in rousing him, there’s no way I’m gonna convince him to walk up a steep hill for 10 minutes in the cold and dark.

And I can’t carry him and the toboggan. And Max? Well, who knows about Max.

After a second meltdown over Sam’s insistence on singing Hey, Soul Sister in an off-key falsetto – actually, this one had me screaming for relief also – he’s in what my wife would describe as a “fragile” state: distant, remote, a little frayed around the edges. Certainly not prone to doing me any favours.

Still, it doesn’t hurt to ask.

“Max,” I say, trying to keep the urgency out of my voice. “Do you think you could pull the toboggan up the hill?
for me while I carry Sam?”

He looks at me, unsure what to make of my request. “We’re out of snow,” I explain. “And Sammy is asleep.”

I’m racking my brain, trying to figure out the neural code for compliance. I know it exists, if I can just punch the right buttons.

Wait, what was that thing I heard him talking about the other day – something from a TV show or library book? Ah yes...

“This is a job for Super-Max!” I pronounce, pinpointing his current fascination with superheroes. “And if you help me with your little brother, I’ll give you 10 cents for your piggy bank.”

Somehow, this appeal to both heroism and fiscal responsibility works. And without a word, my developmentally challenged four-year-old picks up the rope and starts lugging the toboggan up the hill for me without complaint.

Atta boy, Max. At moments like this, it’s easy to forget the raging id monster beneath the surface, the beleaguered, emotionally distraught little boy who struggles to make sense of the world around him.

Max, as he tells me daily, isn’t afraid of anything. He has superpowers. He’s Super-Max.

If he can believe it, so can I.

---

**Stranger in a Strange Land**

**IMAGINE YOU ARE VISITING A COUNTRY WHERE YOU DO NOT SPEAK THE LANGUAGE.**

by Kevin Reinhardt

**EVERYONE SEEMS NICE** – busy, but nice. You really need to communicate; you cannot get what you want or where you want to go without somehow connecting with these people. They want to include you but no one seems to have the time to deal with the strange foreigner. Some of them are almost rude about it. For your part, you want to understand, you try to understand, but it is just so difficult.

Many of us have been in this position; even as I write, some of us are living it as international students in Canada. As an English-speaking traveler in foreign countries I have looked for the “loud” Americans just so that I could hear language that I understood. With them I could converse without having to constantly struggle to understand and to make myself understood. I wasn’t always struggling to do the “right” thing when I was with them. I could relax.

I often hear from students who are struggling with the English language and Canadian culture, that their real pleasure is to listen to music or watch videos in their mother tongue or go out with friends from their country of origin. It is relaxing. They do not have to be on guard all the time for language and cultural or social mistakes that they might make.

Now imagine that there is no going home from this country. There are no friends or family from your country of origin with whom you can retreat to relax and re-energize so as to be able to confront the confusing and perplexing world around you once again. You are completely and utterly alone in this foreign land.

This is what it is like to be one of the one in 94 Ontarians to be born with Autism.
Uncomfortable clothing, odours, noise, even temperature and lighting can be so distracting that paying attention in class or studying at home becomes impossible. Sometimes we feel so overwhelmed, so confused, so anxious, so alone, that we just give up. We wonder if the classmates that we never got to know, who were put off by our uninflected voice or the way we abruptly started and ended conversations or stood too close when we talked to them, ever think about us after we are gone. Does the professor wonder what happened to us or is he just relieved that that strange person with the know-it-all attitude or the incessant questions is gone?

Not all of us give up. Some survive on their own. They are the individual heroes. More of us survive because the people around us make an effort to get to know us, to understand us and accept our differences. We will never be completely comfortable in your foreign world. It will always be a struggle. It can be a struggle which allows us to flourish. Most of us, we just need a little help and understanding. We often make errors in scheduling and organizing appointments and deadlines. We can get so caught up in doing what we see as a good job on a particular paper that we forget to leave time to do other assignments. We arrive a week early for that Thursday appointment and after dealing with the embarrassment, forget the actual appointment and have to reschedule – another embarrassment.

And the chaos around us! There is just too much noise and activity. There are things around here that a hundred, maybe a thousand different people touch every day. That can just be too potentially dirty for some of us to tolerate. The odours coming from the cafeteria and the Tim Horton’s are overwhelming, and not always in a good way. We are used to particular kinds of food and all this new stuff is so different and not what we are expecting. Sometimes it is better to go hungry than to brave the cafeteria.

Other students make comments about how we seem to wear the same clothes every day. We try to keep ourselves and our clothes clean but wearing the same kind of clothing every day makes life so much easier. Imagine wearing someone else’s clothing, two sizes too small and made of scratchy, heavy canvas or slick and cold plastic. Every minute you are wearing such a garment your attention is focused on your discomfort. It’s almost impossible to think about anything else. Any clothing that feels “wrong” is distracting to a person with ASD. Our clothes have to fit and feel just right. Features such as a pocket to hold your phone or wallet are good organizing tools, relieving us of the worry of losing stuff. Once we’ve found the perfect clothes, we want to keep wearing them so that we can relax enough to do our work. We dread the day that the manufacturer goes out of business or changes the factory that makes it.

Uncomfortable clothing, odours, noise, even temperature and lighting can be so distracting that paying attention
Surf’s Up!

ALOHA TORONTO BRINGS HAWAII AND AUTISM AWARENESS TO ONTARIO

by Brad Cotton

AT FIRST GLANCE, the Aloha Toronto event held each year in the Toronto Beaches looks like any other festival. There’s live music, food, drinks, vendors and loads of bathing-suit-clad revelers of all ages on the sand and in the water. It’s only when you take a closer look that you see the real magic of the weekend celebration.

Aloha Toronto founder, Helen Hatzis, got the idea for the festival in 2009, while attending the famous Paskowitz Surf Camp in California. That’s when Helen met Izzy Paskowitz, the former #1 ranked surfer in the world, and his wife Danielle.

In the middle of the weeklong surf camp, attendees were invited to participate in something called Surfers Healing, a foundation for autism. Surfers Healing was started by the Paskowitz couple in response to something that hit very close to home. Izzy and Danielle’s son, Isaiah, has autism.

The Pakowitzes quickly learned of the calming effect the ocean had on Isaiah. His meltdowns would cease and he would spend entire days bonding with his father on the waves. Izzy and Danielle were overwhelmed by their son’s response, and they wanted to share this experience with others. Surfers Healing was born.

Surfers Healing is a collection of renowned surfers from Hawaii and California that now host free surf camps for children with autism across North America. They take children who span the autism spectrum into the water and introduce them to surfing, stand-up paddling, or just to the flow of the rippling waves. When Helen witnessed the inspiring foundation with her own eyes for the first time she turned to Izzy and said, “We need to do this in Toronto.” To which Izzy replied, “Tell me when you’re ready.”

The first year for the Aloha Toronto event was 2012, and it was a smashing success. The two-day camp saw an incredible response from children with autism who participated, and from their families, who all attended for free. Tears of joy were shed, photos were taken and shared, and the Toronto beaches were home to a great time for a terrific cause.
This year’s event promises to be even bigger and better as Aloha Toronto, now aligned with Autism Ontario as well as Surfing Healing, expands its reach into the autism awareness community.

On April 2, Aloha Toronto participated in World Autism Awareness Day as guests of Autism Ontario. It was the first time that Canada was officially part of the World Autism Awareness Day celebration and Aloha members were on hand to see the Autism Ontario flag rising at Toronto City Hall, one of over 400 flags across the province raised that day.

After the reception, Aloha Toronto team members headed out to the streets to film more autism awareness videos. One such video asked Torontonians, “Do you know what today is?” The response was posted on YouTube along with the other videos produced by the group.

As Aloha Toronto 2013 approaches, the team is hard at work planning for another great event; raising funds, organizing volunteers and looking for corporate sponsors. Izzy and his pals from Surfing Healing, including big wave Guinness Book world-record holder Garrett McNamara, will all be back. The first day of the two-day free surf camp for children with autism is already full, and less than half of the spots remain for Sunday.

This year, Aloha Toronto will be held at Cherry Beach on August 24 and 25. The weekend will be jammed packed with live entertainment, food, drinks and even a special appearance by Hawaiian native and CFL Most Outstanding Player of 2012, the Argonauts’ Chad Owens. To kick off the weekend, a Hawaiian themed party will be held at the Balmy Beach Club on Friday, August 23. All the surfers will be there, as will many other special guests, including the award-winning Spirit of Aloha Dancers. The party will also feature authentic Hawaiian drinks and a silent auction, with proceeds from both going to Autism Ontario and Surfing Healing.

So this August, when the sun is out and you’re looking for something fun to do with the whole family, join Aloha Toronto, Surfing Healing, and Autism Ontario for not only one of the greatest outdoor festivals of the year, but for a truly great cause. It will be a festival unlike any you’ve ever seen.

For more on Aloha Toronto and the charities they support, visit Alohatoronto.com.
TOP 10

THE ONE THING YOU SHOULD KNOW BEFORE YOU DIE, ACCORDING TO OLIVIA CHOW, MAESTRO FRESH WES AND MORE

by Michelle Reddick

POLITICIAN OLIVIA CHOW, *Love It or List It*’s Hilary Farr, rapper *Maestro Fresh Wes* and seven other famous notables each took 10 minutes [recently] to talk about the one thing everyone should know before they die. The stacked speaker lineup (and promise of wisdom distilled into sound bites) drew a huge crowd to the Winter Garden Theatre for the third annual Top Ten Event benefitting Autism Ontario. Abiding by the TED Talk-like time limit proved difficult, however – comedian Ron James and a few others ran over their time, while humanitarian Roméo Dallaire joked that “brevity is not a strength of generals.” Below, we round up all 10 key messages.

**Olivia Chow, Member of Parliament, former city councillor**
The Message: Find your peace
The Highlights: Chow elicited sighs and excited murmurs when she announced she wanted to “tell a story about falling madly, passionately in love at age 16.” However, the object of her affection in this case was not her late husband Jack Layton, but the Canadian wilderness. While working as a junior forest ranger in Northern Ontario one summer, the grandeur of her surroundings made her own problems seem insignificant, and helped her to locate a lifelong source of peace and contentment.

**Roméo A. Dallaire, retired general, senator and author**
The Message: We’re all in this together
The Highlights: Dallaire explained that technology has made the world small, which means ignorance is no longer excusable and being an engaged global citizen is obligatory. With both passion and precision, he laid down three ways to begin: 1. educate the world’s women; 2. move from a culture of mere tolerance to one of respect; and 3. travel the world – “see it, touch it, smell it, and bring it back.”

**Linda Lundström, fashion designer**
The Message: Embrace failure
The Highlights: Lundström charmed the crowd by admitting she graduated high school with a 53 percent average because she was usually up until 3:00 a.m. the night before a big exam making an outfit. The designer’s line was a huge success before it imploded in the financial crisis of 2008, and she spoke movingly about losing everything, even her home. Lundström now sees “big, fricken’, life-altering failure” as a crucial experience. “When it comes, welcome it,” she said. “It brings gifts: humility, empathy, and simplicity.”
Alison Smith, CBC news correspondent
The Message: We have more in common than we think
The Highlights: Smith had the audience in tears with an anecdote about covering the funeral of Princess Diana, where she noticed a small white card on top of the casket with the word “Mummy” written in a child’s handwriting. The moment helped her to realize that “no matter how famous or glamorous she was, she was a mother, like me.” Her next story drew chuckles: while covering Pope John Paul II’s funeral and viewing, she saw that his right foot was askew. In the midst of such elaborate ceremony, the moment struck Smith as hilarious and humbling and made her realize that “our imperfections unite us as humans.”

Wes Williams, aka. Maestro Fresh Wes, rapper, record producer, actor
The Message: Expectation, operation, destination
The Highlights: The Maestro bounced around the stage while relating how some of his biggest disappointments – like when a first grade classmate told him he couldn’t be a hockey player because he was black – were precursors to his biggest successes. Sadly, he did not rap, but the elements of his three-step plan for success did rhyme: find your passion and keep moving forward (expectation); put in the work (operation); and celebrate your wins (destination).

Deepa Mehta, film director and screenwriter
The Message: Communication is everything
The Highlights: The director was worried she might have to drop out of the event because she was too busy to write a speech, so host Stuart Knight offered to interview Mehta onstage instead. She told him people are most afraid of the unfamiliar, stressing that communication is key in overcoming awkward confrontations with the unknown. Asked which recent films moved her, Mehta mentioned the French film Amour, (“It’s really about communication in unexpected ways”) – but also the Disney animated flick Brave, which she called a “good old-fashioned feminist film” with a touching mother-daughter story. “I wasn’t expecting Brave!” said a flabbergasted Knight.

Bruce Cox, executive director of Greenpeace Canada
The Message: The power of one
The Highlights: Like Dallaire, Cox cut straight to his message within moments of stepping on stage, expounding on the power of a single vote. “Governments don’t lead, they follow,” he said. “They follow the votes; likewise, corporations follow the consumers.” Cox also explained that Greenpeace routinely asks how they might reach just one person because all social movements are made up of inspired individuals. A quote from Springsteen brought the point home: “You can’t start a fire without a spark.”

Rose Reisman, health and wellness expert
The Message: Take care of yourself
The Highlights: It’s easy to see how Reisman has managed to author no fewer than 17 bestselling books – her talk included a long list of ways to improve physical and mental well-being. She urged the audience to seek balance, to find a passion so you “never work a day in your life,” and to avoid fast-fix diets because an all-or-nothing mindset is a bad way to approach anything in life.

Hilary Farr, designer, co-host of Love it or List it
The Message: Every emotion has an upside
The Highlights: “This is so outside of my comfort zone,” admitted Farr, jokingly asking, “Am I supposed to be telling you the design tips you must know before you die?” She then explained that vanity led her to take the speaking gig, and as a result, she was doing something new and scary – a sign that even “negative” emotions can yield benefits. “Vanity is a cultivatable asset!” she half-joked. She implored her listeners to derive edge and courage from anger, and to seek in every emotion the opportunity to learn.

Ron James, comedian
The Message: Follow your own plan
The Highlights: James’s bon mots covered everything from his inauspicious start in acting to the absurdity of Tim Horton’s coffee (“When did they wrap themselves in the flag? It wasn’t brewed on the slopes of Vimy in the heat of battle, guys!”). The key message, however, was to follow your bliss and not worry about what others are doing. “People think you can have it all right away,” he said, “but you gotta do the work.”

Host Stuart Knight

Event photos: Rick O'Brien
I LOVE SURPRISES, so unlike many expectant mothers, I did not want to know the sex of the baby growing daily in my belly. With most decor options being very girl or boy in design, I chose the ever gender-neutral “Classic Pooh” theme. Warm greens and yellows adorned the walls and we papered some character cut-outs throughout the room. It was a quiet, tranquil spot – our own “Pooh’s Corner” right in our house.

When my son Aidan was born I rocked and nursed around the clock in our peace-ful cocoon of A.A. Milne’s famous characters. When visitors came, he very loudly commanded his mother, his room and his food source. I was burning out. Nursing a baby every two hours 24 hours a day is not good for anyone: mentally, physically and emotionally. He was thriving, gaining on average a pound a week – a typical “bounc-ing baby boy.” I was growing resentful of Piglet’s and Pooh’s ever-watchful eyes and the Hundred Acre Wood was closing in on me. Multiple attempts to stick a bottle in Aidan’s mouth (with the good stuff – expressed breast milk) were dismal failures, resulting in much fussing and not much else. I needed some help.

Like any modern, educated person, I went searching on the internet. The World Wide Web of infinite knowledge and answers for all maladies offered no useful suggestions. Apparently, I should love nursing my baby, and the more the better. After six

Excerpted from the author’s forthcoming book The Purple Notebook: [to be published in 2014]. Excerpt edited for this publication. For more excerpts: http://thepurplenote.bogpsnat.ca.
months, I did not agree with the majority of other nursing mothers out there. So I went to my doctor, who, as a working parent with three, was realistic and sympathetic. The only solution was to “cold turkey” the poor boy. Aidan was healthy, robust and starting solids so the sudden lack of breast in his life would certainly not affect his constant growth rate.

Aidan’s weaning plan was as involved as the A.A.’s Twelve Steps. I was imposing a sobriety plan to a junkie, except I was the drug and my six-month-old was addicted to breastfeeding. My mother-in-law volunteered on that fateful day so that I could stay away, out of range. I left behind a bountiful supply of breast milk and sterile bottles for the taking – but he didn’t, until 10:00 p.m. that night when he gulped down his first bottle. I thought, “I have a stubborn one to raise,” but I think I was a little off the mark.

Difficulty to transition. Needing routines and daily rituals. These are common traits for children on the spectrum. I was infant Aidan’s daily ritual, and I took that away. I never really faced the guilt that I felt and still feel about my need to suddenly, without warning, take away something so critical for this little guy. Nine years later, I still remember every moment from that day and wonder if my decision to remove his nursing safety-net has had any long-term effects.

But we continued to rock many nights away, in Aidan’s land of lush green and calming yellow. He loved everything Winnie-the-Pooh. I did not have the rigorous nursing schedule, but still had many nights interrupted. A soft touch and a hushed voice would lull him back into comfort and slumber. He needed to know I was there. A huge benefit was that finally Dad could also provide late night cuddles, and that really cemented their bond.

Looking back at the situation, I know that it was the routine that Aidan was “addicted” to, not my breast. He needed that regular contact, that escape from the noise of everyday life. So while the urgency lessened, the need was still there. Pooh Bear and friends have remained a constant in Aidan’s life too. His collection of Milne books rivals any bookstore or library and his decor still reflects his preference to be cocooned in the land of Christopher Robin – bedding, curtains, artwork – all courtesy of Ernest H. Shepard’s original sketches.

Our experiences, we hope, can help others. We can reflect now upon Aidan’s behaviours as an infant and now. The single most important thing we have given him is love, unconditionally, and Pooh Bear and all the rest of his Hundred Acre Wood pals have remained with us for the ride.
Le trouble du spectre de l’autisme (TSA) et l’anxiété

POURQUOI NE PAS TOUJOURS INCLURE L’ENSEIGNEMENT DE L’AUTORÉGULATION?

par Anne Borbey-Schwartz,
Coordonnatrice des services de soutien aux familles,
Régions de l’Est et du Sud-Est


L’anxiété semble dominer les rubriques. Toutefois, peu de recherches visent à mieux comprendre l’impact de l’anxiété sur nos enfants et adultes ayant un TSA. Les résultats suggèrent que plus de 55 % des personnes ayant un TSA éprouvent des troubles anxieux et ont besoin d’un soutien pour comprendre et gérer leur anxiété. La gestion de l’anxiété étant un des principaux obstacles à la participation communautaire pour bon nombre de personnes autistes, l’apprentissage de l’autorégulation doit commencer en bas âge et faire partie d’un plan d’enseignement à long terme. S’attendre à ce que nos enfants s’adaptent naturellement aux pressions externes et qu’ils développent eux-mêmes les outils nécessaires pour composer avec leur anxiété peut mener à une augmentation de celle-ci et à une réduction de leurs habiletés sociales.

Il existe de nombreux programmes pour enseigner l’autorégulation. Tony Attwood, psychologue de renom et spécialiste des troubles du spectre de l’autisme (TSA), a conçu une trousse d’enseignement de l’autorégulation. La « boîte à outils émotionnels » a pour but d’aider les gens à faire face à leurs émotions négatives. Cette ressource vise l’atteinte de deux objectifs : réduire l’intensité de l’émotion vécue et aider la personne à comprendre le rôle des pensées face aux situations d’anxiété. L’enseignante, Kari Dunn Buron, a créé un outil de résolution de problèmes et d’autorégulation « L’incroyable échelle à 5 points », dans le but d’enseigner la rétrospection et l’analyse de la solution. Ces deux outils sont très efficaces pour l’enseignement de l’autorégulation. Pas question cependant de tenter de les incorporer dans toutes les leçons. Les deux sont des mécanismes d’intervention et non de prévention. Cette information me semble préoccupante parce que, dans le domaine de l’autisme, l’autorégulation est souvent reléguée à l’arrière plan. Ces dernières années, les interventions telles que l’orthophonie, l’ergothérapie, l’intervention comportementale intensive sont fortement recommandées et je crois sincèrement que l’enseignement de l’autorégulation devrait être ajouté à cette liste.
En Ontario, depuis une dizaine d'années, l'intervention comportementale intensive est l’approche préconisée pour les enfants ayant l’autisme. Cette approche vise l’apprentissage d’habiletés cognitives et met l’emphase sur le développement du langage réceptif et expressif.

Cette thérapie est intensive et chaque enfant reçoit au délà de vingt heures par semaine d’enseignement suivant le modèle des comportements verbaux (Skinner 1957). Les sessions sont axées sur les réponses rapides qui indiquent une connaissance fluide de la matière, et les enfants bénéficient d’un plus large éventail de leçons individuelles. Bon nombre des enfants qui suivent cette thérapie voient leurs habiletés cognitives s’accroître, mais continuent d’éprouver de la difficulté à gérer leurs émotions, surtout dans les environnements stressants comme l’école ou la collectivité. Dans ces conditions, la perte de contrôle est souvent attribuée à l’impulsivité.


Imaginons que chaque intervention incorpore cette procédure? Que ce soit en orthophonie ou en intervention comportementale intensive, l’enseignement de la pause avant de répondre pourrait devenir une habitude. À la longue, l’enfant généraliserait cette habileté, faisant une pause avant de réagir ou de prendre quelque décision que ce soit. N’est-ce pas ce que nous faisons chaque jour? Avant de perdre patience, je prends une petite respiration, ce qui me permet de placer tous les éléments en perspective. Si cette habileté est tellement importante pour nous, les « neurotypiques », pourquoi ne pas l’enseigner aussi aux personnes ayant un TSA? La solution me semble assez simple : En incorporant l’enseignement de l’autorégulation à nos leçons, nous faisons en sorte que les enfants et les adultes ayant un TSA soient adéquatement outillés. Toutes nos interventions futures auprès de cette population vont non seulement inclure un élément d’autorégulation, mais seront également fondées sur la compréhension de l’importance de la pause de questionnement.

**BIBLIOGRAPHIE**


À l’aventure avec Savon Quilave !

**BONJOUR**, je suis tellement heureux de participer à ma première activité d’apprentissage social francophone à Sudbury. Est-ce que vous me voyez ? Je suis confortablement installé sur la tête de mon meilleur ami Dominic. Ah ! j’oublie de me présenter, je m’appelle Savon et mon nom de famille est Quilave; mon nom est donc Savon Quilave et c’est Dominic qui m’a donné ce nom original.

Dominic et moi, nous prenons notre temps pour regarder le bateau de pirate, les jeux de parachute et le château avec nos nouveaux amis.

Commentaire d’un parent : « Je suis reconnaissant à tous les bénévoles qui m’ont donné la chance de parler avec les autres parents sans m’inquiéter des petits. »

Pardon, je dois vous quitter pour l’instant, j’ai l’estomac qui gargouille, c’est le temps de manger. Il y a tellement de bénévoles du programme d’orthophonie de l’Université Laurentienne. Merci !
Wow ! Bradyn, Skyler et Noah ont participé à toutes les activités, même la classe de Zumba. Quel entrain!

Pendant les diverses courses, les jeux de souque à la corde et de parachute, madame Carole me dit « que moi et Dominic pouvons participer à notre propre rythme et à notre façon ». De plus, elle dit « que c’est bien de faire des choses différentes et que c’est pour cette raison qu’elle organise des activités pour nous et nos familles ».

Ah ! Il ne reste plus de place. Voici une petite photo de moi, Dominic et sa soeur Annick, je crois qu’elle aussi a eu du plaisir. J’espère vous revoir. À la prochaine aventure !

De Savon Quilave.
LE PROGRAMME POTENTIEL PREND SON ENVOL DANS
LA COMMUNAUTÉ FRANCOPHONE DE HAMILTON-
NIAGARA

par Chantal Mudahogora,
Coordonnatrice des événements
communautaires francophones,
Régions de Hamilton et Niagara

« …Un événement impressionnant. Merci de fournir une occasion aussi spectaculaire
à nos enfants d’apprendre et de socialiser dans un environnement confortable… »

VOICI LE TÉMOIGNAGE d’un parent d’un enfant ayant un TSA, qui a participé à une occasion d’apprentissage social en français dans la région de Hamilton-Niagara, l’automne dernier.

Les enfants ayant un TSA ainsi que leurs familles ont eu l’occasion de participer à des activités de cirque. Des familles de différents coins de notre région étaient au rendez-vous; elles étaient venues de St-Catharines et d’Oakville pour se joindre aux familles de Hamilton, Burlington, Stoney Creek, etc.

Avec l’aide d’animateurs formés à cette fin, les enfants ont vécu une expérience agréable en participant à des activités physiques et d’initiation aux arts du cirque, offertes dans un environnement sécuritaire et sous le signe du plaisir. Cet événement a offert aux jeunes une occasion de développer des habiletés et de prendre conscience de la souplesse et de la force de leur corps en pleine croissance.

Plusieurs activités étaient à l’ordre du jour. Des jeunes de tous âges ont pratiqué l’acrobatie; ils ont sauté sur le trampoline, se sont balancés sur le trapèze et ont fait de la jonglerie. Bref, les jeunes ont fait la tournée des différents appareils et en ont essayé plusieurs.

L’événement s’est terminé par une période de socialisation et une dégustation de pizzas. Les enfants se sont bien amusés et les parents ont eu l’occasion d’échanger avec d’autres adultes sur leurs expériences, de faire du réseautage et surtout de rencontrer les familles nouvellement arrivées dans notre région. Ces familles ont d’ailleurs exprimé leur reconnaissance à l’endroit du programme Potentiel qui les aide à sortir de leur isolement dans un milieu où elles appartiennent à une minorité.

À la suite de cette activité, au moins 90 % des parents se sont dits satisfaits de leur expérience et tout à fait à l’aise avec l’idée de revivre une activité semblable avec leurs enfants.
Le deuxième magazine *Info Autisme* entièrement en français est prêt !

**NOUS SOMMES FIERS** de vous annoncer que le deuxième numéro spécial du magazine *Info Autisme* est prêt. Vous y trouverez des histoires inspirantes, des stratégies gagnantes, des renseignements utiles, des preuves de dévouement à la cause et de belles œuvres artistiques créées par des élèves ayant un trouble du spectre de l’autisme (TSA). La rédaction et la production de ce deuxième numéro spécial d’*Info Autisme* ont été rendues possibles grâce à la Bourse Canada-Ontario accordée à Autisme Ontario.

Autisme Ontario a sollicité l’aide des conseils scolaires pour faire en sorte que chaque famille d’élèves inscrits dans les écoles de langue française de l’Ontario en reçoive un exemplaire. Le magazine sera aussi distribué aux fournisseurs de services régionaux. Si vous n’avez pas reçu votre exemplaire du magazine et en désirez un, veuillez en faire la demande par courriel à rpcfrançais@autismontario.com ou par téléphone au 1-800-472-7789, poste 239.


Une troisième composante de la Bourse est la création de deux lexiques et un glossaire anglais-français. Les lexiques touchent les domaines des TSA et du système scolaire de l’Ontario, et le glossaire présente la terminologie de l’analyse comportementale appliquée/analyse appliquée du comportement. Pour accéder à ces ressources, veuillez visiter le site Internet d’Autisme Ontario et cliquez sur la « Section française ».

Autisme Ontario tient à remercier toutes les personnes qui ont contribué au succès de ce deuxième numéro d’*Info Autisme*, entièrement en français. Le résultat de cet engagement se trouve dans les 56 pages du magazine.

Bonne lecture !

---

**Renseignements en français**

LA JOURNÉE DU 2 AVRIL 2013 n’est pas passée inaperçue à l’École secondaire catholique Monseigneur-de-Charbonnel. Certains élèves ont souligné de brillantes façons la Journée mondiale de sensibilisation à l’autisme. Dans le cadre de leur programme d’études, les élèves du cours « Introduction à la psychologie, à la sociologie et à l’anthropologie » ont conçu une campagne de sensibilisation de leurs pairs à l’autisme. Ce projet, qui ne devait qu’avoir une visée scolaire, a priori, a permis aux élèves de la classe et de l’école d’abattre des barrières et de démystifier des préjugés.

**Pourquoi ce projet?**

Le projet a été élaboré spécifiquement pour le 2 avril afin de présenter une vision positive de l’autisme. Le but était de sensibiliser les gens, de démystifier les préjugés et de proposer une vision plus inclusive pour notre école et nos élèves. Le projet a permis de découvrir que l’ONU (Organisation des Nations Unies) avait statué sur l’adoption d’une Journée mondiale de sensibilisation à l’autisme en 2007 et que le Canada avait officiellement emboité le pas en 2013. Les élèves ont ainsi eu l’occasion de suivre en direct de quelles façons la ville de Toronto soulignait l’événement et d’en mesurer les impacts sur leur vie réelle. Le projet a permis également de mieux comprendre les diverses caractéristiques des TSA (troubles du spectre de l’autisme) et de mieux comprendre quelles sont les similarités et les différences dans le développement plus conventionnel d’un autre enfant. Pour certains élèves, le projet fut également source de tristesse lors de certaines études de cas plus approfondies. Des sentiments d’injustice et d’impuissance nous ont envahis en découvrant que ceux et celles qui ont
un diagnostic de TSA sont généralement traités de manière défavorable et avec insensibilité.

**Découvertes sur les TSA**

Pour plusieurs de ces adolescentes et adolescents de la onzième année, cette activité fut enrichissante sur le plan personnel. Certains élèves ne connaissaient pas les caractéristiques liées aux TSA et voyaient les personnes autistes comme des extra-terrestres, comme appartenant à un autre monde où se vivent des expériences différentes des leurs. D'autres croyaient qu'ils souffraient de maladie mentale et les plaçaient tous dans le même panier. Pour d'autres encore, leurs conditions étaient simplement terrifiantes et ne les poussaient guère à vouloir les approcher.

L'existence d'une Journée mondiale de sensibilisation à l'autisme n'était pas connue de l'ensemble des étudiant(e)s de la classe et cette découverte a grandement aidé à modifier leur perception. Entre autres choses, les élèves ont appris que les autistes ne sont pas tous les mêmes et qu'ils peuvent présenter des caractéristiques qui les rendent uniques. « Nous avons aussi appris que plusieurs personnes célèbres peuvent avoir eu du succès dans la vie même si elles avaient un TSA ». « Nous avons également appris qu’il n’existe pas de traitement curatif ».

« Nous savons aussi que certains aspects de la vie quotidienne des gens qui ont un TSA peuvent être améliorés, notamment grâce à la technologie. L’utilisation des ordinateurs et des tablettes électroniques peut leur permettre de s’exprimer librement ». « Certaines interventions sont tentées pour améliorer leurs conditions de vie, mais chaque personne réagit différemment ».

**La Journée mondiale de sensibilisation à l’autisme**

Les élèves ont remarqué que la Journée a été célébrée dans plusieurs pays dans le monde. Les journalistes francophones, entre autres, ont présenté des cérémonies dans plusieurs municipalités ontariennes, ce qui a suscité plusieurs réactions. « Ce projet m’a permis de leur donner une chance, dans le sens que maintenant j’essaie de les comprendre au lieu de les fuir ». « Ce projet m’a ouvert les yeux sur l’importance de cette Journée. Ça m’a également permis de réaliser qu’il y a d’autre chose qui se passe à l’extérieur de mon monde et que cela peut être plus important ». L’ensemble de ce projet et les découvertes réalisées par le biais de cette Journée mondiale de sensibilisation à l’autisme permettront certainement aux élèves de jeter un regard plus positif sur les gens qui vivent plus en marge de la société. L’amour et l’acceptation seront dorénavant à l’honneur dans une école où l’inclusion de tous occupe une place prépondérante.

---

**Ressources**

**Webinaires en français**

La Table provinciale francophone pour la personne handicapée : http://www.personnehandicapee.on.ca/

**Le Centre Genève pour l’Autisme** : www.autism.net (cliquez sur Éduc-Autisme)

**Publications d’Autisme Ontario** : www.autismontario.com (cliquez sur Section française)

- L’importance du social, vers de meilleures interventions axées sur les habiletés sociales, pour les Ontariens ayant un trouble du spectre de l’autisme

**Autres ressources en ligne** :

- Info Autisme : numéro spécial en français
- Conseils Autisme : fiches-conseils sur des sujets variés
- Lexiques : Trouble du spectre de l’autisme (TSA), système scolaire de l’Ontario
- Glossaire : Analyse comportementale appliquée/analyse appliquée du comportement (ACA/AAC)

**Pour vous procurer des ressources** :

- www.autisme.qc.ca
- Mille merveilles : http://www.millemerveilles.com/
- Les pictogrammes : http://www.lespictogrammes.com/
- Base de connaissances d’Autisme Ontario : http://autismontario.novosolutions.net/default.asp?id=0&Lang=2&SID=
- La fédération québécoise de l’autisme : www.autisme.qc.ca
- Mille merveilles : http://www.millemerveilles.com/
- Les pictogrammes : http://www.lespictogrammes.com/
- Pour vous procurer des ressources :
  - http://www.libraryducentre.com/
  - http://autismawarenesscentre.com/
  - product-category/livres-en-fran-ais/
Ce rapport sommaire se veut un bref aperçu des cinq grandes composantes du programme Potentiel d’Autisme Ontario. L’efficacité du programme et l’efficience de son modèle de prestation de services sont indéniables. Y sont mis en évidence : six années de services adaptés aux besoins des familles d’enfants ayant un TSA; des actions revendicatrices en leur nom; et surtout, des mesures pertinentes qui font contrepoids à l’incapacité de nos collectivités de répondre aux besoins de ces familles.

« Merci pour votre excellent travail. Mon enfant profite réellement de tout ce que vous faites pour lui. Le soutien que vous apportez à tous ces enfants témoigne de votre bonté et de votre gentillesse. »

Partie du quilles du temps des Fêtes, Le 31 décembre 2012, Région de York

Autisme Ontario tient à exprimer sa reconnaissance au ministère des Services à l’enfance et à la jeunesse de l’Ontario pour sa contribution au programme Potentiel.
Book Review

The Spark: A Mother’s Story Of Nurturing Genius

by Kristine Barnett, reviewed by Monica Richardson

THE EXTRAORDINARY MEMOIR of a mother’s love, commitment and nurturing, which allowed her son, originally diagnosed with severe autism, to flourish into a universally recognized genius – and how any parent can help their child find their spark.

Today, at 13, Jacob is a paid researcher in quantum physics, working on extending Einstein’s theory of relativity. Diagnosed at age one with severe autism, at three he was assigned to life-skills classes and his parents were told to adjust their expectations. The goal: tying his own shoes at 16. Kristine’s belief in the power of hope and the dazzling possibilities that can occur when we keep our minds open and learn to fuel a child’s true potential changed everything.

I am a fan of most of the books that make it to Heather Reisman’s recommended reads, so when I saw The Spark I was intrigued, and when I discovered it was a true story of a young boy with autism, I knew it would make it to the top of my pile.

The book left me with a mixture of feelings and thoughts. Yes, it was inspiring, and no doubt young Jake will go on to make brilliant advances in science and math. Yes, his mother was brave and relentless, and insightful to see what her son was capable of. And yes, she helped so many other families... so I should feel really good, right?

Well, not entirely. As a mother of a young man who would be completely on the other end of the spectrum from Jake, I cannot help but wonder if this book will have the uneducated reader thinking of the movie Rain Man and the savant genius. This may not help with the relentless advocacy so many of us do for the cause, and for those on the spectrum who don’t have an IQ off the charts, who really need the services of professionals and cannot function nor progress in a similar daycare setting. Will it cause the general public to think that some of us overreact? I sincerely hope not. While I applaud the work Khristine did, and feel joy that her son is doing as well as he is, we cannot forget the reality of life where a mother has to leave her son on the steps of a Ministry office because she is hopeless, or where young children wander off to the sound of water and don’t come home.

Read the book, but remember that Jake is but one of thousands of individuals with an ASD and not all are fortunate enough to be a “genius,” but each one does have at least one “spark” and we need to find it, ignite it and let it grow to its potential. And like Kristine, the parents of all our children are brave and relentless advocates.
MY NAME IS SCOTT SMITH. I have Aspergers and I’m proud of it. It makes me special, as all kids are.

Last year, when I was in Grade 5, I started an anti-bullying club at Belfountain Public School. I involved our local businesses and the community.

Sadly, because of having Aspergers, I would get bullied at school. Many other kids get bullied as well. I started the club to help all kids that were getting bullied. With the help of some of my classmates, my Principal and my family, we quickly had a website, and raised money to buy anti-bullying T-shirts. We sold 200 T-shirts using the profits to bring in groups to the school and talk to us about bullying. The club got a lot of attention; we have had inquiries from other schools in Ontario, the United States and even Australia.

Every student at Belfountain signed a pledge not to bully, making our school the only bully-free school in Ontario.

Kids with Autism or Aspergers all have good ideas. You just have to make them happen.

Scott Smith
Belfountain, Ontario

www.antibullyingclub.net

NOT FORGOTTEN

If you care about someone with Autism, please help us to help them!

In order to successfully advocate for adults with Autism and Aspergers we need you to add your voice.
Go to our website www.autismontario.com/adults and fill out the ‘Count Me In’ registration form. This registry consists of adults living with ASD in Ontario, their family members, their supporters and their service providers.

Numbers are powerful tools to take to Ontario Government leaders. Please don’t wait, complete the form today.

Those who need services and supports are counting on you!

Ontario Partnership for
Adults with Aspergers and Autism

COUNT ME IN!

AutismONTARIO
As anyone who has ever chaired a meeting can tell you, the most challenging aspect of it is balancing the need to move through the agenda items with the need to ensure that all participants have the opportunity to weigh in on the discussions. Such was the case at our recent Board meeting of April 26-27, a 24-hour period chock full of information and stimulating conversation.

Of particular interest were updates from Autism Ontario staff. Katherina Symes, Community Resources Manager, shared with us the exciting success story of flag-raising ceremonies throughout the province on April 2, World Autism Awareness Day, officially recognized in Canada for the first time. Through the generosity of BMO, over 500 flags were raised in municipalities across Ontario, and it’s expected that there will be even more next year. We also heard from Marilyn Thompson, Director of Family Programs and Services, who shared an update on all the wonderful things that have been happening with the Potential Programme over the past year, and from Gayle Height, Finance Director, who gave us the fourth-quarter financial report for 2012-2013, which shows a picture of solid financial health for the organization. We met Katharine Buchan, who has recently come on board in the brand new staff role of Educational Materials Coordinator, and received an exciting and encouraging fundraising update from Ramneek Jeer, Fundraiser and Executive Services Administrator.

In addition to learning about things that had already taken place, we also learned of some exciting developments in the greater autism community. Researchers Stelios Giorgiades, Briano DiRezze, and Irene Drmic of McMaster University spoke to us and invited our input on a proposal for SPOR – Strategy for Patient-Oriented Research. This strategy would see the establishment of a collaboration to support the transition of youth with neurodevelopmental disorders and severe mental illness into adulthood. Everyone around the table agreed that there would be great potential for Autism Ontario to play a key role in such an important initiative. Similarly, the Board’s input was sought by Executive Director, Marg Spoelstra, regarding the establishment of a Network of Excellence (NOE), a proposed virtual one-stop site that would highlight best practices in autism services. While both SPOR and NOE are merely in the talking stages at this point, it’s heartening to see just how much active interest there is in autism-related issues, with a level of widespread engagement we could never have imagined even a decade ago.

It is just such interest and engagement that inspires and motivates us as a Board to keep forging ahead in our mandate to ensure that Autism Ontario remains a relevant, committed, and passionate voice for all Ontarians with autism and those who care about them.
Who’s Who on our Board
– Janet Culliton

What is your role on the board?
I’m one of the newer members of the Board, having joined in June 2012.

Why do you enjoy volunteering with the board?
I was involved in Autism Ontario as a SEAC rep for almost 15 years, and was a founding member of our local chapter Huron-Perth. It’s rewarding to now be volunteering at the provincial level, and to use the skills I’ve accumulated in business over the years for something so meaningful. It’s a really interesting time to be involved in Autism Ontario – there is so much going on. The Ombudsman’s report is expected to be released soon which hopefully will help bring about improved levels of support. There has been a lot of interest in autism from the media, including the CBC, and the Toronto Star with their series The Autism Project, so awareness and concern about autism has never been higher. There are several new areas of important research underway, and new partnerships are being created to further the interests of individuals on the spectrum. When I get discouraged about the future of my special daughter and others like her, I just try to remind myself that positive changes in the future are almost certain. We all just wish they would hurry up.

What’s one thing you’d like members to know about the board?
We’re all there for the same reason. There is a genuine level of care and commitment and respect for individuals on the spectrum and their families. And we’re all well aware of how much work is still left to be done.

Tell us a little about your family:
My husband Gerry and I (married for 27 years) live in Stratford, Ontario and have two beautiful girls, Grace and Ruth-Anne. Grace is 24 and lives at home with us. She has autism, the kind that requires a very high degree of support, so she keeps us on our toes. Grace is also a gifted artist and has won awards for her work. She was the Geneva Centre’s poster girl back in the year 2000, and won a Temple Grandin award the following year. She has her own website www.graceart.ca and her own YouTube video, Brushes with Grace. Our other daughter, Ruth-Anne, is 22 and has just finished University, graduating with a business degree.

What book are you reading right now?
I recently finished a classic I had always wanted to read, John Steinbeck’s East of Eden. It’s a family saga – a Cain and Abel story, and I found it totally engrossing. Steinbeck’s insights into human nature are brilliant. There are whole courses at some US colleges devoted to studying this one book. Steinbeck dedicated the book to his two sons, and told them he had put everything he had into writing it. How often can any of us say that we have put everything we had into something, that there wasn’t anything we had left undone? I wanted to see what kind of book that would be. I wasn’t disappointed.
This summary report of Autism Ontario’s Potential Programme reflects the five key components that define the program. It provides evidence of program effectiveness in a cost effective service delivery model. This report highlights six years of responsive service to families; ensuring the voices of families with ASD are heard, and, most importantly, that gaps in our communities are supported with effective programs to meet these families’ needs.

Thank you for all your hard work. My child truly enjoys everything you do for him. You are very kind and sweet for helping all these children.

Holiday Bowling, December 31, 2012, York Region

* Autism Ontario gratefully acknowledges the support of the Ontario Ministry of Children and Youth Services for this programme.
ACSF:SC Project Update III - April 24, 2013
Introducing the first official draft of the...

The ACSF:SC is a Classification Tool for preschool aged children with ASD – Not a Test! Not a diagnostic Tool, assessment Tool or checklist!

The ACSF:SC can be used by – Parents, who really know the abilities of the child being rated and the Professionals who work with them; Educators, Clinicians...

Key characteristics of ‘social communication’ illustrated in the ACSF:SC Tool are: a child’s intent for communicating, skills and strategies and ability to reciprocate.

Five classification levels, one being the most functional
Each level is a word picture that describes what social communication abilities of preschool aged children with ASD look like - NOT the WHY!

We have completed Phase I of the project which was devoted to developing the Tool and User Guide. In Phase II, we are currently recruiting participants to help us test the ACSF:SC Tool, to make sure it can do what we want it to do; describe and classify preschoolers with ASD by their social communication ability. Parents are being asked to rate their child using the tool and then to choose two professionals to do the same. Everyone who participates will be asked to provide feedback about the ACSF:SC Tool and User Guide to help us understand how it is used and works. To see an overview and updates about this three-year funded project please visit us at http://www.canchild.ca/en/ourresearch/autism_classification_system.asp.

Psssst...FYI – ACSF:SC is an easier way to say Autism Classification System of Functioning: Social Communication (which frankly, we know, is quite a mouthful).
ACSF:SC TOOL
Autism Classification System of Functioning: Social Communication

Attention Parents of preschool aged children 3-5 years old with Autism Spectrum Disorder.

You are invited to help field test a new tool called the ACSF:SC Tool.

The ACSF:SC is a new strengths-based tool designed to classify (categorize) preschool aged children with ASD by their social communication abilities.

What it is intended to do is to describe what children CAN do, in a way that is standardized for children with ASD and is easily understood by parents and professionals (clinicians, educators).

We are recruiting participants from May to August 2013. If you participate you will be asked to complete a study package by mail which includes:

• a Consent form
• a Participant Information Form (information about you and your child)
• The ACSF:SC Tool & User Guide
• A questionnaire that asks about how you used the tool to classify your child and what you think of it

We will also ask you to recommend one or two professionals (e.g. clinicians, educators) that know your child's social communication abilities to complete similar information. This will tell us if people understand and use the Tool in the same way or differently. Each participant may be asked to complete this package a second time, two-four weeks later. The package takes about 30 minutes to complete.

For more information
If you think you might be interested in participating, please contact the ACSF:SC Project Coordinator and Knowledge Broker at CanChild, McMaster University:
Martha Cousins
905-525-9140 Ext. 27849 or e-mail: mcousin@mcmaster.ca

Give it your BEST SHOT

The days of saying, “I wish I had my camera here...” are long gone. Now that everyone has a camera in their pocket or handbag, wonderful moments are being captured and shared everywhere.

Autism Ontario encourages you to share your special moments with us. If you attend a chapter event, or if you have a story to tell about your family’s journey with autism, we’d love to hear from you.

While photos taken with cell phone cameras and other devices can produce good quality images these days that are especially useful for online viewing, it is important to remember that the quality of photos used in a printed publication such as Autism Matters, requires a higher resolution image. If you are taking photos of an autism event in your community, please set your camera at its highest settings for resolution, and pay special attention to details such as backgrounds, contrast and focus. Then send your images to us with accompanying information about the event, the names of people in the photo (and their permission to use the photo), and the name of the photographer.

Everyone say, “Cheese!”

Photo credit: BigStockPhoto.com/486384
In Your Corner

THIS IS YOUR SPACE TO SHARE CHAPTER ACTIVITIES, GENERATE IDEAS AND FIND WAYS TO FILL GAPS LOCALLY

by Erin Roza, Chapter Development Coordinator and Katherina Symes, Community Resource Manager

THINGS NEVER SEEM TO SLOW DOWN for Autism Ontario chapters. With April 2 marking World Autism Awareness Day, not only did they participate in Raise the Flag events around the province, but many planned events of all kinds – awareness, educational and fundraising – to celebrate the day. Continue reading for a taste of some of the fundraising initiatives, past, present and future, as well as a welcome to new leadership volunteers.

Fundraising activities are critical to a chapter’s ability to support their community. Listed below are some highlights from the past few months. The Peterborough Chapter held a successful Bowl-a-thon in February to support their local initiatives, attracting 30
bowlers and raising over $2,000. Watch for their Yard Sale coming soon. The **Windsor Chapter** held their 13th annual *Give Your Heart to Autism* gala, which raised $150,000 and saw more than 1,000 attendees! The **North Bay Chapter** jumped on the bandwagon this year with their *Tulips for Autism* gala, complete with a *Thumbs Up for Autism* table, signature drink and live auction. With 60 guests in attendance and raising over $7,000, this first-ever event was a smashing success. Another first-time event was **Hamilton’s Slots and Trots**, hosted by Flamboro Downs. A favourable outcome means this won’t be the last.

Many chapters planned their events to coincide with World Autism Awareness Day, hosted on April 2 or throughout the course of the month. The **Wellington Chapter** shone at their *All That Glitters* gala, with more than 100 people in attendance to support the chapter. The **Durham Region Chapter** held their second annual *Girls Nite 4 Autism* in April, where women had the pleasure of shopping from local vendors, while surrounded by like-minded company, enjoying great beats and delicious eats. The **Simcoe Chapter** will have their third edition of the event, *Girlz Nite Out 3.0*, to offer local women an opportunity to sip, shop, savour and socialize, while raising funds and awareness. The **Thunder Bay Chapter** kept busy with two successful fundraisers, *Giving a Scrap About Autism* and *Change for Autism*. The first-ever *Giving a Scrap About Autism* was well-supported by the community (Thanks!) and a huge success, raising approximately $2,000. The *Change for Autism* drive lasted one month ending on April 2, raising more than $470 for the chapter.

We’re now entering event season for the **Niagara Region Chapter**, with third party events Evan’s Ride for Autism, *Cycle for Autism* and a golf tournament coming soon. Also on the horizon is the **Toronto Chapter**’s first annual *Roll and Strike Bowlathon*, with special guest host, YTV’s **CRUNCH** Andy! Meanwhile, the **Chatham Kent Chapter** continues to fundraise at a monthly Bingo. Many thanks to Chatham Riverview Bingo Palace for hosting the repeat event.

As the warm weather approaches, keep an eye out for the many golf tournaments, walks, and cycles coming down the pipe, supporting numerous chapters around the province. Again and again, we thank all the organizers, attendees, volunteers, donors and supporters whose contributions generate successful fundraising events that support the important work chapters, in turn, do to support their communities.

Throughout April and May, all chapters held Annual Chapter Meetings to present a review of the past year and elect new Chapter Leadership Council (CLC) members. We would like to welcome the new volunteers who have stepped up to join our team, and thank the returning volunteers for another year of support in a vital role. We look forward to seeing everyone for CLC training in June.

We wish everyone a bright and sunny summer holiday and look forward to all that it brings. Your continued support is the biggest gift of all. If you have something to include in the next Chapter Corner, please do not hesitate to send it in.

---

**Ingrid Lingman**, Autism Ontario member, volunteer and parent, recently received a Good Citizen Award from the City of Thunder Bay at an award dinner and ceremony. Our Thunder Bay CLC nominated Ingrid and she was successfully selected to receive this prestigious Citizen of Exceptional Achievement Award. Congratulations, Ingrid!

Dana Larrett, Thunder Bay Chapter Volunteer

Photo taken by a proud Scott Lingman.
Families in your community need your help

You can help those families today. Please, consider joining The Champions’ Circle, our dedicated group of monthly donors. You can make a monthly gift in the amount of your choice from your Visa or MasterCard. You save paper and stamps, and you get one consolidated tax receipt at the end of the year; but perhaps most importantly, you make a difference in your community.

There are three ways to become a Champion today!

• Contact info@autismontario.com to join The Champions’ Circle
• Donate online at www.autismontario.com (click on the Donate button)
• Mail your cheque, payable to Autism Ontario, to 1179 Street West, Suite 004, Toronto, ON M6K 3C5

Thank you for your generosity, and for helping us to help others see the potential!

They walk beside you
They may pass unnoticed
You may see them
Once they stand away
Seem different
Off on the side
In their own space
In their own movements
In their own world
They may make you laugh
Maybe you will get angry
Or, you may just shake your head
Walk away in disgust
They do not wish to harm anyone
They are just different than most
They are the invisible
They want to fit in with you
They may want to be your friend
There is a part of them that tries so hard
But they cannot change who they are
They cannot change what is real and true
So they will forever walk alone among you
They are the invisible
They are autistic

Nancy Getty
www.aspergerus.com
A new, bilingual, searchable database of brief, easy-to-understand documents that are relevant to the lives of youth and adults with ASD and their families.

Une nouvelle base de données bilingue et interrogable ainsi qu’une série de courts documents faciles à comprendre concernant la vie des adolescents et des adultes ayant un TSA et celle de leurs familles respectives.

Visit
WWW.AUTISMMONTARIO.COM

Visitez
Autism Ontario Celebrates 40 Years of Providing Advocacy and Support to Individuals with Autism Spectrum Disorder

In 1973, the Ontario Society for Autistic Citizens was formed by a group of parents who came together to support their children with autism. Since that time, what we know now as Autism Ontario has become the most significant parent voice group in Ontario.

This year, Autism Ontario plans to celebrate by highlighting the tireless advocacy and growth that has occurred within the 28 Chapters across Ontario over the past 40 years.

Throughout the year we will recognize this milestone in various ways.

We urge all of you to embrace this anniversary in your local communities.

Happy Birthday Autism Ontario!

Please stay tuned throughout the year for more information.