

Autism

Fall 2020 • Volume 17 • Number 4
A PUBLICATION OF AUTISM ONTARIO

MATTERS

Dealing with Stress
and Anxiety

Pages 10 - 15

Info Autisme



Board of Directors

Pamala Agawa Anishhinaabe-kwe, Susan Boehnke, Tiziana Bontempo (Secretary/secrétaire), Dr. Barry Bruce (Treasurer/trésorier), Hadley Koltun, David Moloney, Kim Moore (Vice President/vice-présidente), Susan Morris (President/présidente), Sharon Smile, Sophia Tsouluhos, Lisa Vezeau-Allen

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

OUR VISION: Best Life, Better World, Making Autism Matter!
OUR MISSION: Creating a supportive and inclusive Ontario for Autism

Autism Matters© 2020 has been developed by Autism Ontario. The editing team of *Autism Matters* strives to include a range of views about ASD and its impact on people. These views may or may not reflect the views of Autism Ontario. No commercial involvement of any kind has been solicited or accepted in the development of the content of *Autism Matters*. Advertising does not influence editorial decisions or content. The appearance of advertising in *Autism Matters* is neither a guarantee nor an endorsement by Autism Ontario of the product, service, or company or the claims made for the product in such advertising. A special banner will indicate to readers of *Autism Matters* advertising features of the product, service, or company they provide.

Autism Matters is published four times per year. *Autism Matters* welcomes contributions from its readers. Send your articles, reviews, letters, comments, announcements, etc., to Michael Cnudde, *Autism Matters* Content Editor. For advertising rates and inquiries contact GEPM Group Inc., info@gepmgroup.com.

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

Editing, design and printing services, GEPM Group Inc.
www.gepmgroup.com

What's Inside FALL 2020

features

- 3 **Press Release Statement from Autism Ontario**, by Marg Spoelstra
- 4 **10 Practices that Contribute to a Successful ABA Program**, by Carobeth Zorzos, Joan Broto and Meaghan Robbins-Dreni
- 6 **Moving and Shaking**, by Patrick Jachrya and Brianne Redquest
- 8 **My Quarantine Story**, by Bekki Semenova
- 8 **Facing Stress in the Age of Anxiety**, by Stephanie Moeser
- 16 **A Summer Like No Other!**
- 18 **Love on the Spectrum**, by Michael Cnudde
- 19 **Autism Ontario Scholarship Awards**
- 21 **2020 Gerry Bloomfield Award Winners**, by Michael Cnudde
- 23 **Ethics in Autism Research**, by Michael Cnudde
- 24 **We Believe in C.A.R.E.** by Susan Morris
- 26 **BMO Supports Autism Ontario's Adult Services Programs**, by Monica Richardson
- 29 **In Your Corner**, by Brittany Sherwood

book reviews/poem

- 27 **Start Here, A Parent's Guide to Helping Children and Teens through Mental Health Challenges**, by Pier Bryden and Peter Szatmari, reviewed by Ola Kuzinerz
- 28 **What's Not Allowed? A Family Journey with Autism**, by Teresa Hedley, reviewed by Telah Morrison
- 31 **The Town that Time Forgot**, by Alanna (Ali) Wilson

info autisme

- 10 **Vivre Aspie!** par Anne Gingras
- 12 **Quelles sont vos ressources en français les plus pertinentes?**
- 13 **Je sais pas lire**
- 14 **Réunir les aidants de toute la province grâce au programme CARES du SAAAC**, par Michelle Bascom

Front cover photo by Michael Cnudde

News and Noteworthy



Autism Ontario's Values: CARE

Collaboration – We believe in the power of working side by side with individuals, families and communities to make informed choices about autism.

Accountability – We hold ourselves and others responsible to achieve successful outcomes through high standards of integrity and fiscal responsibility.

Respect – We value equity, diversity and inclusion, and we listen to understand.

Evidence informed – We use and create knowledge to guide our decisions and work.



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.

Dear Friends,

It was with deep concern and sadness, and primarily in support of autistic people and their families, that we made a decision to post a media release on our website about the Alek Minassian court case that is ongoing as I write this. We are posting that statement here so there is no misunderstanding about our views on this pain-filled matter that continues to affect the lives of so many.

Marg Spoelstra, Executive Director

Statement by Autism Ontario: Cultivated Misogyny and Sense of Entitlement Responsible, Not Autism

FOR IMMEDIATE RELEASE – Toronto, Ontario - November 17, 2020

Autism Ontario strongly objects to the defense team of Alek Minassian's characterization of an "autistic way of thinking" similar to psychosis while on trial for the 2018 murders of Beutis Renuka Amarasinghe, Andrea Knafelc Bradden, Geraldine Brady, So He Chung, Anne Marie D'Amico, Mary Elizabeth Forsyth, Chul Min Kang, Ji Hun Kim, Munir Najjar, and Dorothy Sewell, and the attempted murder of 16 others.

Autism is a neurodevelopmental disorder characterized by social impairments and difficulty inferring the thoughts, feelings and emotions of others. It is not characterized by violence or lack of a moral compass. Nor are autism and mental illness synonymous. Too often, the broader underlying factors are ignored, which leads to unfortunate stereotyping. In reality, people on the autism spectrum and with other disabilities are much more likely to be victims of crime, rather than the perpetrators. The myth that autism causes criminal behaviour is exactly that: a myth.¹ Much too often when a person is diagnosed as autistic, their actions are examined exclusively through that lens without considering the broader picture of other influencing factors on the whole person. This is demeaning to everyone.

As a society, we need to move away from the social construction of autistic people and people with mental health issues as scapegoats for violent acts. Instead, we must focus on the proliferation of misogynistic and other supremacist ideas readily available for consumption and woven into our social fabric. These horrific crimes were actions driven by cultivated misogyny and a sense of entitlement, not by autism. Conflating what took place on April 23, 2018 with anything else obstructs our view of what needs to change. ■

¹Crane, Laura, Marasm Katie, Mulcahy, *Is Autism Linked to Criminality?*, 2015, Autism <https://journals.sagepub.com/doi/full/10.1177/1362361315583411>



StoryBlocks.com

10 Practices that Contribute to a Successful ABA Program

by Carobeth Zorzos, M.A., C. Psych., BCBA, Joan Broto, Ph.D., BCBA-D, and Meaghan Robbins-Dreni, MADS, BCBA

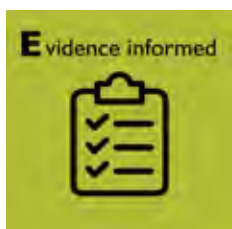
PARENTS OFTEN ASK US about what makes an Applied Behavioral Analysis (ABA) program successful for children and youth with Autism Spectrum Disorder (ASD). We've summarized 10 features below that we feel contribute to a successful ABA program, in no particular order. This list is by no means exhaustive, but we hope this will be a good starting point for families who are exploring an ABA program or for those who are already in an ABA program.

1 Data driven

ABA relies on appropriate and frequent data collection to measure progress and make decisions on next steps. These decisions can include moving ahead to a new step or target, mastery of a skill or goal, when to change procedures and to determine if an intervention is working or not.

2 Individualized

Goals and programs are individualized based on a learner's strengths and needs. This means that assessments need to be conducted before starting any behaviour



intervention or skill development program. Goals are monitored using data collection systems, and changes or revisions are made based on the learner's progress.

3 Collaboration with other service providers

An ABA practitioner should work with other service providers and those involved in the learner's life, including but not limited to speech language pathologist, psychologist, school teachers, educational assistant, healthcare practitioner, occupational therapist, daycare therapist, daycare provider and others. Through collaboration, we can ensure that we work toward the same goals and provide opportunity for skill maintenance and generalization.

4 Parent/caregiver involvement and training:

Parents/caregivers are key members of the ABA team. Their involvement is essential in developing goals and providing feedback on a learner's progress and challenges at home. Parent/caregiver training should be part of all ABA programs to ensure that skills are transferred to the home setting. Training should include clear instructions on the skills being taught, followed by modelling, practice and feedback until parents/caregivers can independently and accurately demonstrate the skill.

5 Developmentally-informed goals

Goals developed in conjunction with parents/caregivers should consider where the learner is at in terms of their overall development. For example, ABA programs for young children with autism will likely teach skills within the context of play and other fun activities to maximize engagement and increase the likelihood of generalization to other settings such as daycare and school.

6 Culturally attuned

ABA programs should take into consideration a family's cultural practices and values. This includes asking questions about how the ABA team can support and respect the family and learner in their cultural practices. ABA practitioners should educate themselves on the principles of cultural safety, ask questions and reflect on their own behaviour in an effort to become more culturally attuned.

7 Follows ethical guidelines

Similar to other healthcare services, ABA has formal ethical guidelines for practitioners to follow. These are outlined by the Behavior Analyst Certification Board (BACB) in the US for those who are certified, and resources are publicly available by the Ontario Association for Behaviour Analysis (ONTABA). These resources outline what parents should expect from an ABA practitioner in terms of professional and ethical behaviour.

8 Clear goals

ABA goals should be clearly defined in terms of short-term and long-term outcomes, whether it is a behaviour to increase or decrease, and when a goal is considered completed or mastered. Goals should be reviewed regularly and updated as the learner makes progress, based on their data.

9 Regular parent communication

Regular parent/caregiver communication is essential for parents to be informed and involved in their child's ABA program. Communication through written or verbal updates provides the opportunity for ABA practitioners to share information on the learner's daily progress and skills to target at home. It also allows for parents to share information on the learner's day at home or school, and provides the opportunity to ask questions.

10 Fun!

ABA practitioners should incorporate their learner's interests into their teaching to maintain a positive rapport and to ensure that their learners are having fun. For young children, incorporating teaching goals within play is an excellent way to target current learning goals through play by maintaining a learner's interest, maintaining a positive relationship with the client, increasing motivation to respond and generalizing their skills across a variety of toys and activities. ■



AutismONTARIO Learning Resources

Visit autismontario.com/learning-resources



Autism Ontario's learning resources are here to assist you on your journey from diagnosis onward.

Webinars | Fact Sheets
Helpful Articles | Personal Stories
Archived Issues of *Autism Matters*
and more...



StoryBlocks.com

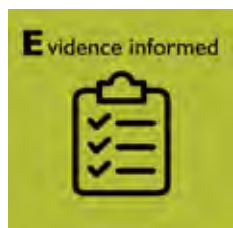
Moving and Shaking

THE IMPORTANCE OF PHYSICAL ACTIVITY FOR PEOPLE ON THE SPECTRUM

by Patrick Jachyra, PhD and Brianne Redquest, PhD

PHYSICAL ACTIVITY PARTICIPATION has been associated with many benefits for people on the autism spectrum. Individuals who are regularly physically active are more likely to experience improvements in their physical health (e.g., better heart health) and also experience improvements in mental health (e.g., decreases in stress and anxiety). Additionally, being physically active can contribute to a sense of structure and routine, and provide increased opportunities to potentially engage in social opportunities to form peer relationships. Finally, people on the autism spectrum who are physically active are also more likely to experience the emotional pleasures of movement such as senses of fun and excitement, and the release of pent up energy or feelings which at times can make us feel overwhelmed, anxious, stressed out and can contribute to a meltdown.

Despite the many benefits of physical activity described above, individuals on the autism spectrum are less likely to be active than their age-related peers. From childhood through to adulthood, individuals on the autism spectrum are less likely to participate in school-based and community programs, and less likely to meet daily recommended physical activity guidelines. These lower levels of activity can be problematic as individuals on the autism spectrum are less likely to benefit from the many pleasures of movement described above, and inactivity can potentially increase risks



for physical and mental health challenges throughout the lifespan.

While there have been many calls to try and increase physical activity among individuals on the autism spectrum, we have come to discover that there are many barriers which often limit participation. From a lack of opportunities in school/community settings, and lack of knowledge among physical activity leaders (school teachers, instructors, coaches) on how to deliver physical activity for individuals on the spectrum, through to challenges with movement skills (running, jumping, throwing), and sensory factors (over-stimulation), being active is incredibly complex. We recognize this complexity and are part of a group of researchers trying to minimize these barriers. While we recognize that more work is needed to move beyond these barriers, we also offer a few ideas below based on our research and experience working in this field as one way to potentially increase activity participation for individuals on the autism spectrum. If you are interested in learning more, please see our blog post on the Autism Ontario website for a few live links related to physical activity, and to also watch the Autism Ontario webinar we did in June, 2020.

Doing activity as a family

Doing activity as a family can be fun and a great way for everyone to be active. It may be helpful to set a goal together such as going for a 15-minute walk each evening after dinner. Try to build up the amount of time (e.g., 15 minutes to 20 minutes each day), and try to increase the frequency of the walks (for example once in the morning and once after dinner) if

possible. When you make physical activity fun, and simply a part of your day, you are more likely to do it.

Incorporating physical activity throughout the day

Breaking up activity into chunks throughout the day might be one way to be more active. For example, try to do something active for 5-10 minutes a few times throughout the day rather than doing 30 minutes of activity all in one block. Another effective way of incorporating physical activity into your day is to add exercise to a task you do often, such as using the washroom or washing your hands. For example, each time you go to use the washroom, do five squats or five jumping jacks. Or, after finishing an activity such as doing a board game, puzzle or watching TV, try to do something active for five minutes. Without even realizing it, these small chunks add up throughout the day to 30 or more minutes.

Examples of physical activity

Physical activity often is associated with sport, and although sport is one way to be active, there are many other ways to be active. Physical activity, for example, comes in many forms, such as active transport (walking or cycling to school/work/errands). Other forms of physical activity that we have found to work well for people on the autism spectrum include martial arts, online exercise classes, dancing, zumba, yoga, walking or jogging, climbing stairs, skipping, hopscotch, household chores (cleaning, vacuuming or gardening), and body weight exercises (push-ups, sit-ups, jumping jacks and squats). In our experience,

some people on the spectrum enjoy and may prefer doing the same physical activity, while others enjoy trying new ones each month.

Whatever your preference, try to your best to do something active every single day, and have fun while you are doing it.

Patrick Jachyra, PhD, is a post-doctoral fellow with the Azrieli Adult Neurodevelopmental Centre at the Centre for Addiction and Mental Health.

Brianne Redquest, PhD, is a post-doctoral fellow with the Azrieli Adult Neurodevelopmental Centre at the Centre for Addiction and Mental Health. ■

My Quarantine Story

by Bekki Semenova, Self Advocate



I am Bekki Semenova, an autistic teenage girl from Vaughan. I am a proud advocate for autism, selective mutism, and mental health who aims to create more acceptance and change within the community towards autistic and neurodiverse people.

THIS QUARANTINE has affected me in unusual ways, beyond the experience of most people. Before the quarantine started, I have always felt invalidated, not listened to, and I felt like my experiences were made like they didn't exist, even though for me, my experiences were very real. Physically attending school created excruciating anxiety for me, to the point where I felt physically sick, and this resulted in me hiding in bathrooms, skipping classes, and every time I communicated how I felt to my teachers and support staff, their response was, "your education is important, you have to learn to cope with your anxiety and attend class. It's not that hard."

I dreaded going to school every day, it was like the worst thing that could ever happen to me. The sights, sounds and voices of everyone around me were sickening to me. I felt that the school system is not made for people like me, who are autistic and who struggle with extremely severe anxiety and panic disorder. I felt like the staff only cared about keeping students like me in their control, with no freedom. I felt trapped and scared. I felt like the place that should be helping me was only harming me.

When the quarantine was announced, I felt so relieved that finally, someone had listened to me. Finally my needs were heard. Finally, I could learn from the comfort of my home. I even noticed that my marks improved, and I felt overall much more relaxed.



▲ Bekki Semenova

Of course I still struggled with anxiety and depression, but I felt that in the comfort of my home, I could be in my safe place. I didn't feel like I always had to harm my well-being to go out of my way for others. I didn't feel violated like I have always been feeling. I feel that finally, an accommodation was made for me that I have been asking for all this time.

If anyone else is in a similar situation, you are not alone. I hope that by sharing my experiences and sharing my voice, others can also find peace in that they aren't alone and that there is someone else who feels the same way! Our wonderful autism community is here to support each other, and I am so happy about that! Hope you all had a great summer! ■

Facing Stress in the Age of Anxiety

THERE'S A GOOD REASON PEOPLE EXPERIENCE ANXIETY AND STRESS THESE DAYS

by Stephanie Moeser, MSW, RSW
Therapist, Rediscovery Counselling

AT THE TIME OF THIS WRITING, we are well into the COVID-19 pandemic. For many, it's an unknown that by its nature seems unpredictable and because of that, can contribute to the anxiety and stress that they are feeling.

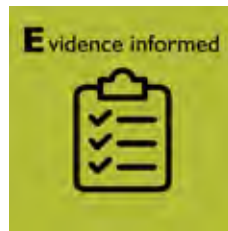
Although it's a normal part of the human condition to have moments where we feel a bit anxious, this is different from being diagnosed with an anxiety disorder, and they shouldn't be conflated. We all feel periods of anxiety, but many experience it in a consistent, invasive and long-term way that significantly impacts their ability to participate in daily life. The purpose of this article is to give a few tips to help you cope with stress. If you have more significant and persistent anxiety, please consider accessing help from a doctor or mental health professional for individualized medical care and mental health supports.

We can do things to mitigate this stress. Remember, we do have control. All of us. That's our power right now. We can start with:

1. Your news feed
2. Positive moments
3. Connections
4. The basics (which are far from basic).

Your news feed

Find the balance for you and your loved ones. If you're a parent, think about how your child is consuming information. Hiding information is not always the best



ARE FEELING MORE

course of action. If your child has questions about what they see online or have overheard on the radio, answer their questions, but don't provide more detail than needed. Keep it factual and to the point. Reassure your child that they can talk to you about their worries and that you will listen. Validate worries, but also provide security. "I know sometimes things feel overwhelming and confusing. It's okay to feel worried, everyone does sometimes. Please tell when you feel this way."

Try not to talk too much about your own worries in front of your child. Although it's important that your children know it's normal to feel overwhelmed and worried at times, as parents we don't want to add to that. We can say something like, "I feel confused and worried sometimes when I hear things on the news, but I know I'm safe at home and I help others be safe by following the public health rules." If you need to talk more about worries make sure your kids are out of earshot.

Know when to turn it off. Find the balance of being informed and being overwhelmed and weighed down with information. Take news and social media breaks. Disconnect for periods of time every day.

Positive moments

We have control over these too! Most importantly, we have control over where we put our focus. I don't mean that we should ignore negative emotions; these are valid and need to be honoured, but we can also choose to notice moments of joy. Take the time to really notice them. Create a positive moments book, or a book of joy. This could be drawings of things you or your child have noticed during the day, a word, a phrase, a list, some leaves from a walk, a photograph. Collect those moments. The more we consciously take time to see the positives and the small (but significant) beauties in this world, the more we *will* see them. It will then be clear that we can hold both joy and anxiety together; both are valid, but the more joy we feel the less the anxiety will take over.

Connections

Take time to connect. We miss seeing friends. We miss seeing extended family. We miss being able to hug friends and loved ones. We have learned over these months how to be creative. Harness that creativity to connect with people in your lives.

Find ways your kids can connect such as board games, video games, coffee dates, movie nights and book clubs online. Go old-school and mail letters! Remember the joy of getting a letter in the mail? You may have your kids write or type letters to their friends. Checking in with each other with a 'thinking of you' can go a long way.

Getting down to basics

The basics are important. Hydration, healthy food, exercise and sleep will support you in managing the ups and downs of life. Drink water. Keeping a glass or bottle near you will help your energy levels and support all the functions of your body. Healthy food is good fuel but allow some treats as well. Exercise, even when it's cold. Winter will be soon upon us and we need to ensure that we are not forgetting to move our bodies and get outside.

Have jumping jack contests, put on snow pants and warm hat and mitts and play in the snow. Walk in the snow. Don't avoid winter. Get out and play (because you know that's exercise too). Sleep. Go to bed earlier than you think you need to. Help your kids go to bed a bit earlier. Read books in bed before sleep. Tip: try to establish a regular bedtime routine for yourself and your kids. Try to stick to it (but forgive yourself if you can't always). This will support winding down before bed.

Remember, we are in this together. Small acts of kindness, and compassion to others and especially to ourselves can go a long way in supporting our wellness. ■



Artwork by Haley Van Camp, Self Advocate

INFO Autisme

Vivre Aspie!

par Anne Gingras

Auto-représentante, parent, enseignante



À 14 h 13 le 21 juin 2011, assise dans le bureau de la psychologue de grande renommée Isabelle Hénault, à Montréal, j'ai enfin reçu un diagnostic qui éclaire maintenant toute mon existence : je suis bel et bien Aspie.

EN RELISANT LES MOTS QUI ENTAMENT *Perspectives d'une Aspie*, un article rédigé en 2011, je souris. Déjà 9 ans se sont écoulés et tout comme la vie, l'expérience en est une qui est fluide et qui apporte ses surprises. On ne dicte certainement pas ce qui en est et ce qui en adviendra, et la façon avec laquelle une personne approche les diverses péripéties qui lui sont présentées est bien ce qui fait la différence—surtout lorsque l'on est une personne qui vit avec le spectre de l'autisme. J'explique.

Commençons avec le côté professionnel. Ma carrière a bien évolué du temps que je découvrais que l'autisme faisait partie de mon quotidien. Toujours enseignante, j'ai eu l'occasion de travailler quatre ans au sein d'un Carrefour qui appuyait les ados autistes avec les habiletés connexes dont ils avaient besoin pour 'réussir' dans la vie. Je témoignais jadis combien ceux-ci avaient de la difficulté avec les choses les plus 'simples' du quotidien, alors que plusieurs possédaient une aisance académique. Ce fut l'expérience la plus révélatrice de ma carrière. Au niveau professionnel, bien que je voyais le progrès de mes élèves, j'ai compris à quel point la communauté n'était pas prête à considérer les différences neurologiques et sensorielles de nous qui vivons avec un TSA. J'ai constaté que tout le monde a sa propre réalité qui dicte ses actions et qu'en bout de ligne, même si on n'est pas autiste—on pense à soi, à ses succès et à sa survie. J'ai appris à devenir quelque peu diplomate, à peser le poids de mes mots et surtout, à ne pas offusquer l'équilibre délicat qui existe au sein des systèmes d'éducation. Dans l'ombre, cependant, j'ai continué mon travail de revendication en parlant à un et à l'autre, en partageant mes observations et en apportant, au fil de mes expériences, cette saveur de diversité et d'inclusion. À mon retour en salle de classe 'régulière,' j'ai remarqué que mes élèves répondaient bien aux diverses stratégies utilisées au Carrefour : boîtes sensorielles, horaires visuels, lumière dégagée ...toutes ces choses qui faisaient une



Crédit photo : Anne Gingras

différence pour les élèves autistes (et moi-même) savaient apporter un certain réconfort et une structure prévisible pour tous mes élèves. À travers ceci, j'ai témoigné des succès académiques importants et plus incroyable encore, un développement social remarquable : politesse, revendication des droits et des besoins et connaissance d'une justice sociale au sein d'une communauté. J'ai vu combien l'empathie peut croître si on l'enseigne de façon explicite, et la différence que celle-ci peut apporter dans le quotidien des autres qui nous côtoient.

Tranquillement, j'ai continué mon cheminement professionnel. En juin 2018, l'Université Nipissing de North Bay me conférait le titre de Dre en Éducation (honoris causa) en raison de mon apport au fil des années de ma carrière. Cet honneur m'ouvrit la porte que j'attendais depuis longtemps : un poste d'enseignante à la Faculté d'Éducation de ce même établissement. En fait, en automne 2019, je me retrouvais devant une classe d'étudiants à enseigner un cours axé sur les besoins particuliers des élèves en salle de classe. Une cinquantaine de futurs mentors me permettaient de me développer davantage, tout en apprenant de mes expériences personnelles au sein d'une salle de classe. Maintenant au poste d'enseignante-ressource au sein d'une salle de classe distincte, je continuais (et le fais toujours) à parfaire mes astuces et à décortiquer ce monde social afin de mieux appuyer mes élèves. C'est une vocation innée pour moi, de pouvoir aider les gens à se découvrir et à se dépasser. Bien que j'aimerais mieux pouvoir rester chez moi à chaque jour au lieu d'être obligée de porter mon masque social, je le fais avec brio puisque je sais que chaque personne rencontrée pourra m'apporter des leçons importantes. À 50 ans, j'ai encore l'impression d'être perdue au sein d'une communauté qui m'accepte pourtant si bien. Je suis une femme professionnelle, membre d'un corps professoral universitaire, enseignante dans une école secondaire.

Mais je suis encore dans ce genre de néant où je comprends encore mal les enjeux quotidiens. Je me débrouille. Je me débats. Je porte un masque (en plus de celui maintenant imposé en raison du COVID) et je suis épuisée. Les gens comprennent encore mal pourquoi j'ai besoin de temps de répit. Je réussis tout ce que j'entreprends. J'ai plusieurs talents que je partage. J'écris et publie des livres. Je compose de la musique. Mais je suis avant tout Aspie—et je suis souvent épuisée.

Cet été, je vivais le moment le plus difficile de ma vie. Après avoir perdu ma mère le 29 février, j'ai pris un temps de congé pour me rebâtir et me retrouver. J'approchais encore une fois le burnout mais cette fois, comme habituée, j'ai reconnu les signes et me suis permis le temps de repos et de reconstruction identitaire. Tout s'est bien passé. J'ai dormi. J'ai marché (plusieurs courses et médailles à l'appui), j'ai écrit et je me suis retrouvée. C'est en juillet que tout a recommencé à se débobiner, alors que nous apprenions comme famille que mon époux avait le cancer du côlon. Suite à sa chirurgie du 23 juillet, il s'est retrouvé aux soins intensifs trois fois. J'ai dû annoncer deux fois à ses enfants et à sa famille que nous l'avions perdu. Nous avons été bénis puisqu'il a défié la mort à deux reprises et est de retour à la maison. Pour toute personne, ces expériences sont assez prononcées et apportent certainement une réponse accrue au traumatisme. Comme personne Aspie, je me suis vue lancée dans un univers inconnu et très fluide, ne sachant jamais d'un moment à l'autre ce que m'apporterait la vie. Comme épouse, j'étais perdue. Comme mère, je me suis sentie impuissante et incapable de protéger mes enfants. Comme personne, je me suis aussi vue me transformer et trouver au sein de mon âme une force que je ne savais pas exister au fond de moi. J'ai réussi à 'survivre' ... et voici comment :

- J'ai suivi une routine. Levée de bonne heure le matin, j'ai poursuivi

ma marche afin de mieux gérer mon anxiété. Je me suis fixée des buts. Chaque pas vers l'avant m'a apporté de l'espoir. J'ai découvert les mantras et la méditation active (que je recommande et que j'enseigne à mes élèves).

- J'ai bien mangé. Un corps en santé apporte des décisions encore plus saines, surtout sous pression. Je n'ai bu aucun vin!
- J'ai gardé des listes dans un petit cahier : choses à faire, questions à poser, éléments à explorer ... l'anxiété et le changement du 'normal' provoquent l'oubli de choses aussi mondaines. Tenir des listes me permet de garder cet équilibre par rapport à ce que je peux contrôler ou que je ne peux pas.
- J'ai fait confiance : médecins, infirmières, experts de la santé. On ne peut pas tout savoir au sujet de tout—et il faut savoir quand lâcher prises.
- J'ai pleuré. Souvent, en fait. Je me suis permise de pleurer à chaque jour et ensuite, j'ai mis le tout 'dans une boîte' et j'ai continué sur le chemin de la vie. Pas facile—mais les larmes n'apportent pas de solutions.
- J'ai bien dormi. Point. Le sommeil est de prime abord.
- J'ai été honnête avec mes enfants, ma famille, mes cadres de travail et moi-même. Il ne faut pas se raconter des histoires. On dit les choses comme elles le sont – et on avance de là.
- J'ai ri et j'ai passé du temps avec mes amis. Il faut savoir décrocher, même momentanément. C'est important pour la santé mentale des gens que nous aimons, et pour nous-mêmes.
- J'ai cherché les moments positifs dans toute situation. Une personne qui m'avait dit quelque chose de gentil, quelqu'un qui m'envoyait un message par courriel, un sourire d'un médecin ou d'une infirmière—toutes des petites choses qui en bout de ligne se sont avérées de plus importantes.

- Enfin, et c'est la clé—je me suis fiée à mes enfants et à ma famille. Chaque action portée—chaque mot parlé fut et est encore en fonction du bien-être de ceux qui m'importent le plus. Ensemble, nous avons grandi et avons forger davantage des liens qui nous tiendront d'ici la fin des temps. J'y crois. Mordicus.

Vivre comme Aspie n'est certes pas facile, mais comme toute chose, on s'y fait. On avance, à petits pas et on sourit à travers un masque imposé. Je continue à marcher, pas à pas, sur la route qu'est la vie ...et j'ai bien hâte de voir ce que l'avenir me réserve. Chose certaine, je continuerai à parfaire mes astuces et à voir le côté positif de la vie. En bout de ligne, c'est ce qui importe et qui me garde solide et heureuse. *Carpe Diem...*

Anne est enseignante-ressource au sein d'une classe distincte. Elle vit dans une petite communauté avec son époux incroyable, son fils adulte et ses trois chiens. Son fils cadet vient souvent la visiter dans ses temps libres. Anne passe ses moments de loisirs dans son Studio et à rêver de Paris. Elle est auteure de trois livres et se prépare à en publier deux autres. Elle continue à bien dormir la nuit. ■



Quelles sont vos ressources en français les plus pertinentes?

LA RECHERCHE DE RESSOURCES EN FRANÇAIS sur l'autisme et les sujets connexes peut être longue et fastidieuse. Une bourse de l'Entente Canada-Ontario permet à Autisme Ontario de faciliter cette tâche par la création d'un répertoire de ressources en français.

Ce répertoire vise mettre en vedette les ressources les plus pertinentes pour la communauté de l'autisme francophone. Pour ce faire, nous vous invitons à nous envoyer des informations sur les ressources que vous gardez à portée de main, que vous proposez aux autres ou auxquelles vous vous reportez souvent.

Les ressources peuvent comprendre, entre autres, des livres ou manuels, des vidéos, des sites Internet ou des applications pour tablette numérique.

Toujours au service de la communauté francophone, ce répertoire servira non seulement de destination première des francophones à la recherche de ressources mais aussi de point de partage de nouvelles découvertes.

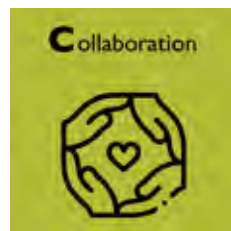
Afin de bien représenter la communauté de l'autisme francophone, nous vous demandons de nous faire parvenir le nom de vos ressources préférées, une courte description du contenu ou de son utilisation ainsi que tout lien pertinent. Vous pouvez faire parvenir ces informations à l'adresse courriel : français@autismontario.com.

Un GROS merci au nom de la communauté de l'autisme francophone. ■



Renseignements en français

Désirez-vous recevoir des renseignements en français? Pour vous inscrire sur notre liste d'envois électroniques, rendez-vous sur le site d'Autisme Ontario, à l'adresse www.autismontario.com, et cliquez sur « Nouvelles ».





Je sais pas lire

DANS *Je sais pas lire, je sais pas écrire, voici mon livre*, Michael Jacques, un jeune adulte déterminé et plein de compassion vivant avec l'autisme et une déficience intellectuelle, nous raconte, sans prétention, ses anecdotes et ses découvertes éloquentes qui nous apprennent à accepter et à célébrer nos différences. Michael, pour qui rien n'est impossible, a écrit son livre à l'aide de la fonction de synthèse vocale d'un iPad et y traite de sujets comme l'apprentissage, l'inclusion, le militantisme, l'indépendance et le pouvoir de la persévérance.

Par sa plume spirituelle et positive, Michael nous offre un aperçu de sa vie et de ses réflexions sur le monde, qui sont poignantes et inspirantes tout à la fois.

Pour commander : heresmybook.com. ■



L'autisme, c'est important

Parents, assurez-vous que l'école de votre enfant favorise l'inclusion des enfants qui ont un trouble du spectre de l'autisme.

Autism Matters contient des articles fort intéressants pour les membres du personnel enseignant et pour les parents. Ces articles sont rédigés par des cliniciens ou cliniciennes, des éducateurs ou éducatrices ainsi que des chercheurs ou chercheuses, ou encore par des élèves et des adultes autistes qui acceptent de nous livrer leurs histoires personnelles.

Les membres d'Autisme Ontario reçoivent automatiquement cette revue trimestrielle. Nous invitons les écoles à s'inscrire comme membres professionnels d'Autisme Ontario. Cette inscription leur permettra de recevoir tous les numéros d'**Autism Matters** et leur procurera aussi de nombreux autres avantages.

Si l'un de vos enfants fréquente une école publique ou une école catholique de l'Ontario, demandez à la direction ou aux enseignantes et enseignants à l'enfance en difficulté de devenir membre professionnel d'Autisme Ontario et continuer ainsi de travailler à faire de votre école et de votre collectivité un milieu de vie inclusif pour les élèves qui vivent avec un trouble du spectre de l'autisme.

Pour de plus amples renseignements, visitez le site autismontario.com.



AutismMATTERS est une publication d'Autisme Ontario.

AutismONTARIO

1179, rue King Ouest, bureau 004
Toronto, ON M6K 3C5

Les membres d'Autisme Ontario reçoivent automatiquement cette revue.



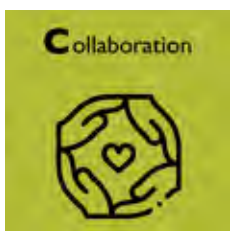
Réunir les aidants de toute la province grâce au programme CARES du SAAAC

par Michelle Bascom - Chef de l'équipe des prestataires des services de navigation pour le Nord

EN TANT QUE PRESTATAIRE des services de navigation pour Autisme Ontario, une de mes plus belles expériences a consisté à unir les aidants naturels de toute la province en période de pandémie. Même si mon rôle m'appelle notamment à organiser une série d'activités et de groupes de soutien dans les collectivités que je dessers, je n'aurais jamais pu prévoir à quel point ce programme a permis à notre équipe de forger des liens avec les aidants de partout en Ontario. L'interruption abrupte de toutes nos activités en personne (notre principal mécanisme de communication et de soutien pour nos familles en Ontario) par la COVID-19 a été pour nous une grande source d'inquiétude. Heureusement, la technologie et le programme CARES nous ont donné les moyens de nous réunir virtuellement et de nous entraider pendant cette période de crise inédite.

Animé par des parents bénévoles et un personnel spécialement formé, le programme CARES offre aux aidants l'occasion de tisser des liens et d'échanger les expériences qu'ils vivent auprès de leurs enfants et adolescents autistes. Tout au long des six semaines du programme, les participants abordent divers thèmes, dont la gestion du stress, la pensée utile, l'auto-compassion et la résolution de problèmes. Ces échanges les aident à réfléchir à leur propre santé mentale et à apprendre des stratégies d'auto-soins.

Le programme CARES s'est avéré une source de réconfort et de soutien pour les participants de toute la province, y compris dans certaines des régions les plus éloignées de l'Ontario. Certaines personnes ont noué des liens et des amitiés qui se poursuivent





Photos: StoryBlocks.com

à l'issue du programme. Comme l'écrit Maria S. : « *Le diagnostic de TSA reçu par mon fils a été un grand choc pour moi. J'ai énormément apprécié pouvoir échanger avec des personnes qui m'ont soutenue durant cette période sans précédent.* » En tant que prestataire des services de navigation et animatrice du programme CARES, j'ai été privilégiée de voir les aidants naturels partager leurs expériences et je trouve une riche source d'inspiration dans leur indomptable résilience et le soutien mutuel qu'ils s'apportent.

Les participants au programme CARES ont exprimé leur profonde gratitude envers le programme. Ils ont également ajouté qu'ils n'auraient

jamais pu y participer et forger des liens avec d'autres parents sans la plateforme virtuelle. Une participante a relaté qu'elle avait déjà fait quatre heures de route, aller seulement, pour assister à d'autres programmes qu'elle jugeait importants. Heureusement, le programme CARES permet aux aidants de participer dans le confort de leur foyer et de n'importe où dans la province. Libérés du souci des déplacements ou de la garde d'enfant, de nombreux parents se sont dits davantage encouragés à participer au programme jusqu'à son terme de six semaines. Participer à cette indispensable plateforme virtuelle et aider à réunir les parents à l'échelle de la province a été

pour moi une réalisation incroyable et une expérience incroyablement réconfortante.

La COVID-19 a causé de nombreuses interruptions dans notre vie quotidienne, mais dans ce cas elle a été l'occasion de créer de nouveaux liens significatifs en mode virtuel. Au vu de tous les commentaires positifs formulés par les aidants d'un peu partout en Ontario, Autisme Ontario espère continuer d'offrir en permanence le programme CARES, via la plateforme virtuelle. Notre prochaine session de six semaines doit débuter durant la nouvelle année; ce sera un plaisir de vous y rencontrer! ■



AutismONTARIO
Ressources d'apprentissage

Visitez autismontario.com/ressources-dapprentissage



Les ressources d'apprentissage d'Autisme Ontario peuvent vous accompagner dans votre cheminement à partir du diagnostic.

Webinaires | Articles utiles
Fiches d'information | Récits personnels
Numéros archivés d'Autism Matters
et plus encore...



A Summer Like No Other!

DRIVE-THRU CAMP AND DISNEY IN THE 'DEMIC

Editor's note: We had originally anticipated publishing this story in a different form in our Summer issue. But, as you know, our plans changed, and so we present these members' stories of what was truly a summer like no other.

► Cristina Morriello

Christina loved the Disney Trivia game, and also enjoyed boxing with her instructor Jill. She liked engaging in activities such as “rock, paper, scissors” with Jill, adding that most of the games ended up in a tie

“I loved boxing,” said Christina. “It’s always a lot of fun.” But her favourite thing to learn was the roundhouse kick and she found herself liking the drills and practicing her punches and kicks. Christina credits much to her instructor. “Jill is very nice, and is a great instructor. She’s so positive and encouraging... It was fun to do the exercises and then talk a little after the session was done.”



Steven Gibson

“The first time we started the Disney Trivia game on the website Kahoot,” said Steven, “me and my mom had a little trouble trying to get into the website and keeping track of our score. We eventually fixed the problem thanks to my technology skills. We finally got onto the Kahoot website and finally got some points on the trivia.”

Despite their difficulties on the Disney Trivia night, Steven and his mom returned to win first place on the second evening. “Since the first trivia night I did, I had a blast with it and had fun playing it.”

◀ Adain Neff

A big movie fan, Adain found felt upset when the theatres were closed in March because of the pandemic, and movies were either being cancelled or delayed. “Because of the coronavirus, I am not able to do my favourite thing which is watching movies in a big theatre.”

However, because he loves movies, it was fun for him to play a movie trivia game, where he was able to help write some of the trivia questions. “The Autism Ontario Trivia game was much more fun than the Disney Trivia I did with my school classmates as the teacher picked all princess questions which were boring.”





◀ York Region Campers

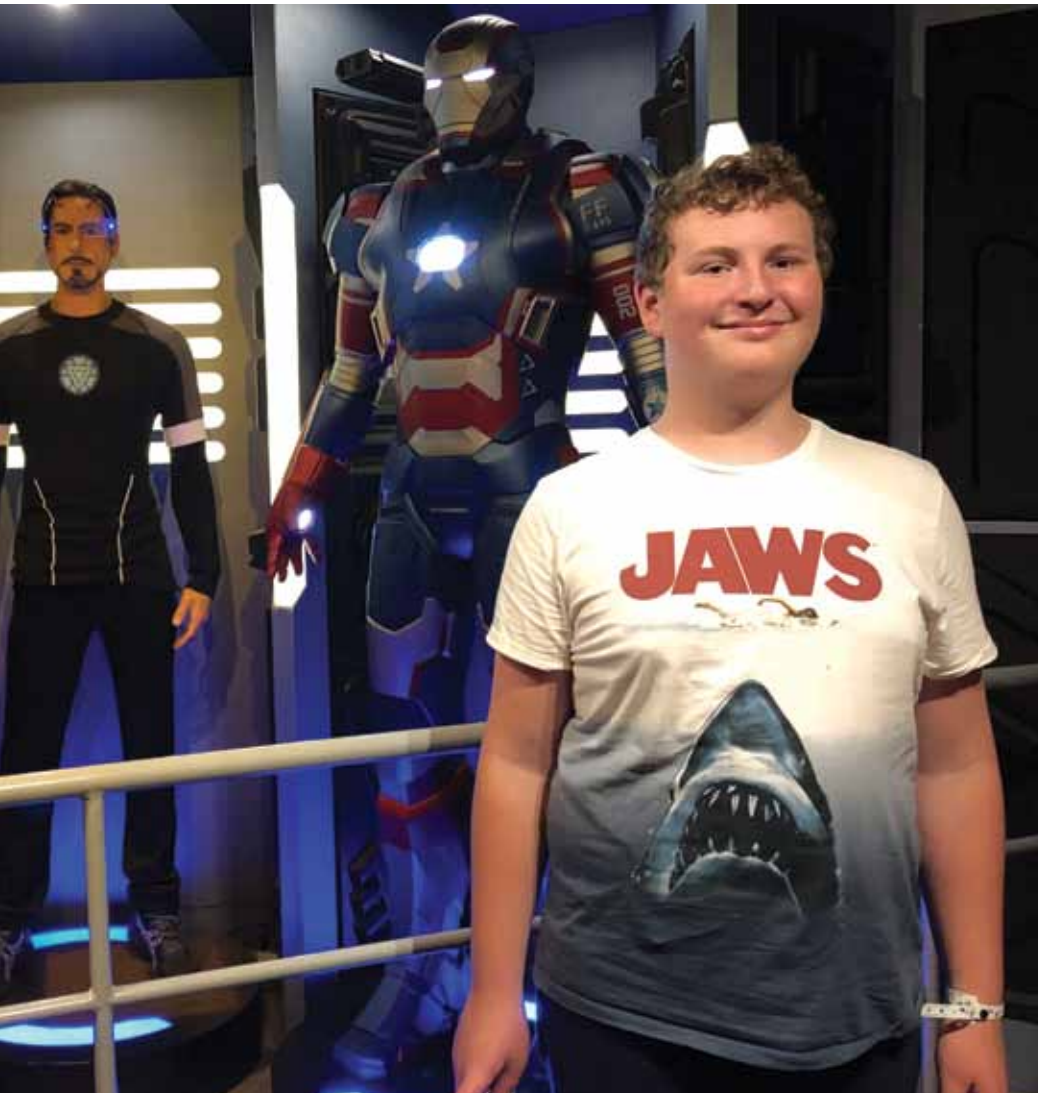
With the COVID-19 lockdown in place, the idea of having a summer camp seemed to be a long shot. That's when the idea of having a virtual camp with some very hands-on activities occurred.

"I knew we would all work hard to make this hopefully unique summer as amazing as we possibly could," said Alex Gardner, York Region Camp and Staffing Director. "We had to come up with something that was both flexible and fun."

The York Region camps were comprised of a Zoom component, where the whole family could be involved—from fitness to crafts to Friday afternoon dance parties—and a hands-on component: the Camp-In-A-Box take-home kits. "Some weeks were filled with fun toys and sensory items while other weeks we switched things up with pizza or cookie kits, to let everyone's creativity shine through," said Alex.

York Region also hosted a Drive-Through Camp in partnership with Willowgrove Camp in Stouffville. Alex said this very popular event allowed campers and families to have a camp experience without leaving their car. "Families drove through the Willowgrove property to see the livestock and beautiful nature trails, stopping at various stations where staff would lead camp spirit sessions, crafts and scavenger hunts," said Alex. "We even had a dinosaur!"

"Thanks to our amazing team, we developed three amazing programs," said Alex. "This may have been a summer like no other, but it's one we won't forget."



Jan McCrea, parent

This summer, Jan wanted to visit her step-daughter Marcy for her birthday. Marcy lives at a Community Living supported apartment, and staff weren't aware that it was her special day. "We needed negative COVID-19 tests to visit," Jan says, "so we waved at her driving by, and we did a face-time call. We miss Marcy..."

Jan didn't have any recent pictures of her step-daughter but she shared pictures of her son Connor, age 20, taken by her daughter Katie. "Many people might feel sad for him that their pool is a tiny plastic tub," she said, "but Connor is very grateful. This is a shot of him relaxing with his goggles on, right before he did what he called 'laps.'" ■



▲ Connor enjoying his pool



Love on the Spectrum

ADULT AUTISTICS REVIEW NETFLIX'S NEW REALITY SHOW

WHEN IT WAS FIRST ANNOUNCED back in July, Netflix's *Love on the Spectrum* caused a big stir in the autism community. The reality show follows a group of young adults on the spectrum as they navigate the world of relationships and dating. While these things are challenging for neurotypicals, they can be even more so for people on the spectrum. How would the show's producers treat their subjects? Would they present a balanced and realistic view, or a critical or sentimental one?

As part of a broader initiative to examine how people with autism are portrayed in the media, Autism Ontario recently asked a panel of adult self-advocates to watch the show and give their opinions.

"I was enthusiastic about it when I first heard about it," says Courtney Weaver, a freelance writer. "There are unfortunate stereotypes that autistic people are incapable of romantic love, or just don't want romantic love. It was interesting to debunk this stereotype."

Aaron Lenc, who works for the City of Brampton, found the series very accessible. "I really liked this show because I want a girlfriend, but I want to learn how to date. I learned from it and it was a good start," he said. He watched all five episodes, first by himself and again with his family. "We paused and talked about what was happening," said Aaron's mother, Tania White. "That was very helpful and a great resource for us as a whole family."



Would you like to take part in future dialogues like this one? Please contact michael@autismontario.com

Each panel member seemed to have their own favourite cast member. For Matthew Lemay, a professional writer, it was Michael, for whom he expressed a feeling of kinship. “I had a few that I liked... I enjoyed Jimmy and Shenae. They were cute as a couple and their experience was lovely. It made me teary.”

Aaron also found the show’s characters relatable. “I liked Kelvin because his autism was like mine,” he noted. “I hope there is a second season.”

In many media portrayals of people with autism, inclusion, fairness and realism are issues, which the panelists discussed. “I agree that people were portrayed fairly,” said Courtney. “With the genre of reality TV, there is a certain narrative and 1:1 interviews and editing take place within this genre. This was done as organically as you can do this.”

Matthew agreed with Courtney, adding, “There are certain editing and narrative decisions in a show that are unavoidable, but people were treated and portrayed as organically and fairly as possible.”

David Moloney, Mutual Fund Indexer with CIBC and Autism Ontario Board member, observed that it is important for producers and writers to listen to people on the spectrum when portraying people with autism. “Often people cast individuals who aren’t representing people on the spectrum as they should be... We should be represented as diverse, appreciated, hard-working, welcomed in society and enhancing the social framework. Inclusion everywhere.” ■

Autism Ontario Scholarship Awards

15 WINNERS FOR 2020

THIS YEAR, Autism Ontario awarded the **Eleanor Ritchie Education Scholarship** for autistic students entering their first year of post-secondary education to seven recipients, including Cornelia Carroll, who is attending the Graphic Design program at Mohawk College. “I am beyond excited,” she says. “I hope that in the future I’ll be able to use my creativity and passion for art in my everyday life, along with being able to inspire others to follow their dreams of getting into visual arts... I would like to say that being given this scholarship has truly given me so much encouragement and pride moving into the next chapter of my life and am full of gratitude to be receiving it.”

Autism Ontario also awarded the **Jeanette Holden Educational Scholarship** to seven students who are siblings of people on the autism spectrum and who are entering the first year of a post-secondary program. One of the scholarship winners, Logan Pickells, who has a younger brother and sister on the autism spectrum, notes that although their family has encountered struggles including bullying, and may not have understood each other because autism affects everyone differently, they have always supported each other. “None of us has been short on love,” he says.

Logan has a disability, and continues to support his brother and his sister, especially during the pandemic when they were forced study from home. He was able



Cornelia Carroll



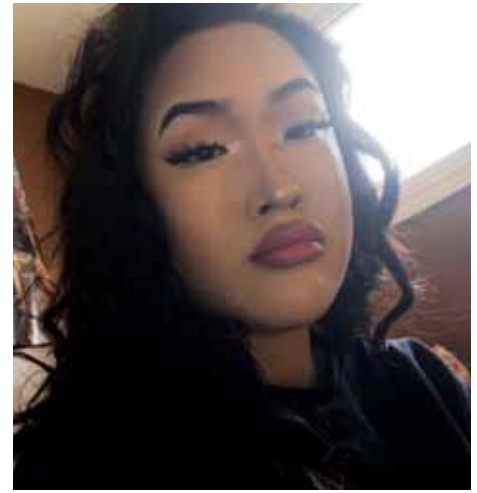
Logan Pickells



Tyler Stephenson, Eleanor Ritchie Education Scholarship winner



Orion Chong, Eleanor Ritchie Education Scholarship winner

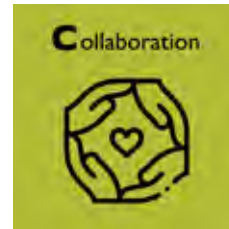


Eunice Hong, Jeanette Holden Education Scholarship winner

to help them with their school work and supported his sister through her late autism diagnosis. He is also an active community member of the Royal Canadian Army Cadets and ErinoakKids, and plans to continue to keep volunteering while attending university. "I feel it is important to pay it forward," he says. "It is important to me to provide the support to youth coming up behind me that I did not always have. I want kids with disabilities to try new things and explore outside their comfort zone. It is when you challenge yourself that you feel the most reward."

The **McDonald Family Educational Scholarship**, for students with a parent on the autism spectrum who are entering the first year of a post-secondary program was awarded by Autism Ontario to Morgan Doucher-Batley.

Congratulations to all the scholarship winners!



Eleanor Ritchie Education Scholarship

- Sarah Knoblauch
- Luc Lamadeleine
- Cornelia Carroll
- Tyler Stephenson
- Evan Thomson
- Jordan Yarmus
- Orion Chong

Jeanette Holden Educational Scholarship

- Maryam Aqeel
- Joshua Damas
- Eunice Hong
- Ayesha Khokhar
- Ahmad Ibrahim
- Logan Pickells
- Carter Hodgins

MacDonald Family Educational Scholarship

- Morgan Doucher-Batley ■

2020 Gerry Bloomfield Award Winners

REFLECTING ON THE PAST AND LOOKING TOWARDS THE FUTURE

by Michael Cnudde, Specialist, Communications and Resource Development

The winners of the 2020 Gerry Bloomfield Award, which is the highest honour that Autism Ontario can bestow on an individual, were announced at Autism Ontario's virtual Annual General Meeting held September 26. This year's recipients, David Baker and Brendon Pooran (co-recipients of the Gerry Bloomfield Professional Award) and Connie Putterman (recipient of the Gerry Bloomfield Volunteer Award) were asked to speak about what future challenges they saw facing people with autism in Ontario.

DAVID BAKER, a lawyer with Baker Law, has represented families of children on the autism spectrum in human rights matters relating to education and intervention, and helped establish ARCH (Advocacy Research Centre of the Handicapped). He provided some context by relating his experience in the early 1980s as a lawyer with the Ontario Association for the Mentally Retarded, helping to shepherd Bill 82 into law. Bill 82 amended the Education Act to require that all publicly-funded schools in Ontario provide education for all children, including those with developmental disabilities. "Prior to that legislation," said Baker, "kids with developmental disabilities were out of school, had never been in school in this province and were being educated by their parents and volunteers in church basements and libraries around the province."



David Baker

Some of the cases Baker's firm has represented have concerned the use of Applied Behavioural Analysis (ABA) in schools. Baker credits past Autism Ontario president Cathy White for helping him see the "false dichotomy" between education and therapy. He noted that the separation of ABA from education is "more to do with cost containment and political concerns ...than ...the needs of students."

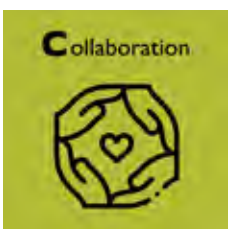
"I think it's autism's turn to have education needs addressed in this province," he said.

LAWYER BRENDON POORAN, of Pooran Law, created his firm to support the disability community and to influence disability law and policy across Canada. He has been involved with different disability organizations at many levels, from volunteer to director. Pooran framed his response to the question of future challenges in terms of the barriers people face consistent to the United Nations Convention on the Rights of Persons with Disabilities. "Canada ratified the convention in 2010 but has far to go with respect to operationalizing it into domestic law."



Brendon Pooran

In his discussion, Pooran touched upon



several points, including legal capacity and the person’s right to make decisions. Laws and policies that discriminate against people who need support in everyday life continue to be developed, he said. The COVID-19 pandemic has exacerbated matters concerned with education for people on the spectrum, further exposing the gaps in the system. Over the last six months, he said, the situation regarding entitlement to supports and affordable housing has deteriorated.

“For a country that has entrenchments in its constitution to promote the rights of people with mental and physical disabilities,” said Pooran, “this is unacceptable, especially given the additional hardships associated with the pandemic.”

CONNIE PUTTERMAN, winner of the Jerry Bloomfield Volunteer Award, reflected on her long-time affiliation in the autism community, which has included Autism Ontario and autism research

organizations across Canada and abroad. Putterman is a leading advocate for autism research and inclusion, representing the parent perspective in these areas, and is the founder of the Canada/Israel Autism Research Initiative. In her remarks, she thanked Autism Ontario Executive Director Margaret Spoelstra, whom she called “a rock and support for me.”

“Back in 2000 when my son was diagnosed with autism,” she said, “through advocacy work done by Autism Ontario and other organizations, Ontario adopted a program to help newly-diagnosed children. We were part of the initial 100 families accepted to the program. Autism Ontario recognized the societal need and most importantly the potential impact.”

Moving forward 20 years, “these kids have been through the system and have grown up and have become young adults,” Putterman said. The province needs a “societal vision” to address the



Connie Putterman

needs of young adults and adults as well. Underpinning it all is the mental health of people with autism and their families. Said Putterman, “My belief is that if we can improve mental health, then it’s a huge accomplishment for the province so people with autism can manage their lives in a positive way.” ■

Autism does matter

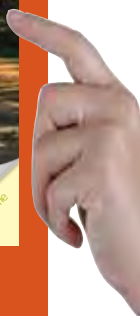
Parents, make sure that your child’s school is an inclusive place for children on the autism spectrum.

AutismMATTERS contains valuable articles for educators and parents, written by clinicians, educators and researchers as well as personal stories by students and adults on the spectrum.

Members of Autism Ontario receive this quarterly publication free. We encourage schools to register as professional members of Autism Ontario, which will give them a subscription to every issue of **AutismMATTERS** along with many other benefits.

If you have a child in an Ontario public or Catholic school, please encourage your school’s principal or special educators to enroll as a professional member of Autism Ontario to make your school and community an inclusive place for students on the autism spectrum.

For more information, visit **autismontario.com**.



AutismONTARIO
1179 King St. W., Suite 004
Toronto, ON M6K 3C5

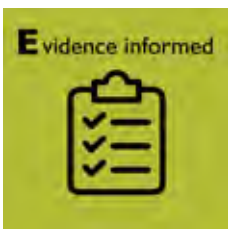
Ethics in Autism Research

INCLUSION AND RESPECT FOR THE INDIVIDUAL

by Michael Cnudde, Specialist Communications and Resource Development, Autism Ontario

WHEN YOU THINK OF ethics in research, you might think it's summed up by asking a participant's permission or getting that signature on a consent form. But it's much more than that. It's about considering the people who are participating in the research and their needs as well. A recent study points to inclusion as a guiding principle of an ethical approach to research. "Everything is underpinned by the respect for the individual," says one of the study's authors, Dr. Ariel Cascio, an Assistant Professor in the Art of Medicine at Central Michigan University College of Medicine.

"Inclusion is a really important part of research," says Dr. Cascio, discussing the study she coauthored, *Person-oriented ethics for autism research: Creating best practices through engagement with autism and autistic communities*. "Researchers want to be inclusive. So thinking about how to make meaningful engagement between researchers and participants becomes very important."



Dr. Cascio, along with her colleagues Dr. Jonathan A. Weiss and Dr. Eric Racine, and a panel of researchers, self advocates, family members, and autism professionals from the Autism Research Task Force published the study in June 2020, seeking to summarize the best ethical practices in person-centered autism research, which considers the research participant and their needs first.

The study highlights five guideposts, important to ethical and person-centred autism research:

1. **Individualization:** ensuring the research process fits the needs of each participant.
2. **Lived experience:** considering the world the participant lives in.
3. **Empowerment:** making it easier for participants to make their own choices.
4. **Respect for holistic personhood:** valuing the input from the participants and considering their needs and strengths.
5. **Focus on researcher-participant relationship:** considering how researchers and participants take part in the research process together.

Dr. Cascio explains that while there is some overlap between guideposts, each one remains distinct. Underlying them all, however, is the idea of respect.



Dr. Ariel Cascio

Respect can be undermined in different ways that can be detrimental to research. It can be innocent and well-meaning, such as when a researcher excuses people they want to protect from discomfort, or a parent or caregiver steps in and decides against the participation of a person on the spectrum. Excluding groups of participants from the study, says Dr. Cascio, may hurt the research process.

Dr. Cascio got involved with autism research as an undergrad studying anthropology at Washington University in St. Louis. There weren't many resources in grad school, she says, but she found the experience valuable. "I had done some research into adolescents and youth on the spectrum... but I felt there was more I could do. I was working with [a variety of] participants, some with a higher level of support needs, some with a lower level."

Dr. Cascio offers suggestions to other autism researchers. It's important to reduce the sensory burden on participants, she says. "Think about sensory environments where the research takes place. Use plain language—provide multiple ways for people to access study so they can participate, such as using the phone or email."

But it's also critical, she says, for researchers who are studying people

We Believe in C.A.R.E.

COLLABORATION • ACCOUNTABILITY • RESPECT • EVIDENCE INFORMED

on the spectrum to read the writings of people on the spectrum in the social sciences and to avoid depending on what she calls “the sole token lived experience participant/expert.”

“Some people might worry about protecting people on the spectrum and wind up excluding certain groups,” says Dr. Cascio, “such as young children, the non-verbal, the LGBTQ community. If you don’t get those perspectives, your research may be not useful.”

Since the original paper’s publication, a second paper, *Person-Oriented Research Ethics to Address the Needs of Participants on the Autism Spectrum*, has been recently published by Dr. Cascio and her colleagues. “It’s very cool because it gives some quick tips and is ethics friendly. ...I’m very grateful to my colleagues Drs. Weiss and Racine and to everyone on the taskforce.”

This project was funded by a Kids Brain Health Network Core Award, the NeuroEthics Excellence and Societal Innovation Core (NESIC; Racine co-PI). Dr. Cascio was additionally funded by the Angelo-Pizzagalli Scholarship of the IRCM Foundation and the Social Sciences and Humanities Research Council of Canada’s Banting Postdoctoral Fellowship. Dr. Racine was additionally funded by a FRQ-S senior scholar career award. You can learn more about the project and subscribe for updates at <https://www.autismresearchethics.net>. ■

by Susan Morris, Board President, Autism Ontario

AS A BOARD MEMBER of Autism Ontario for the last five years, I have always marvelled at how Autism Ontario is so responsive to the changing needs of autistic Ontarians, their families, caregivers, teachers and service workers. As an example, in this past year, two new services were implemented in a matter of months: the OAP Provider List and Service Navigation. With the arrival of COVID-19, all our services had to be reconfigured to a more virtual model.

Every three years, we are required to make sure that what we are doing continues to align with the community we serve and the values that we hold as an organization. In a facilitated session with Autism Ontario volunteers, staff and board members, the organization’s values were updated to the acronym C.A.R.E:

Collaboration

We believe in the power of working side by side with individuals, families and communities to make informed choices about autism.

Accountability

We hold ourselves and others responsible to achieve successful outcomes through high standards of integrity and fiscal responsibility.

Respect

We value equity, diversity and inclusion, and we listen to understand.

Evidence informed

We use and create knowledge to guide our decisions and work.

Here are just a few examples of how volunteers, staff and the board demonstrated the commitment to C.A.R.E across the organization during this past year:

- More volunteers (an increase from 17 to 72) were engaged with the Central West Regional Chapter Pilot Project to plan and collaborate on the implementation of activities.
- Autism Ontario was awarded the Autism Spectrum Disorder Strategic Fund from the Public Health Agency of Canada to train facilitators and safe hike leaders all over Ontario to adapt and deliver two evidenced-based programs by the Canadian Mental Health Association for adults on the spectrum and caregivers of people on the spectrum.
- Autism Ontario partnered with SAAAC Autism Centre to support the Access Counts Conference as well as with CMHA Ontario and BC to translate *Living Life to the Full* curriculum and supporting materials into Tamil.



- The Board of Directors approved new By-Laws to align the governance of the organization with the pending changes to the Non-For-Profit Corporations Act in 2020/21.
- Ken Robertson, a past member of Autism Ontario's Board of Directors and Treasurer, was awarded the Meritorious Service Medal (Civil Division) in July for creating Four Directions Autism, a parent support group that works one-on-one with off-reserve First Nations, Inuit, Métis and Non-Status children with Autism Spectrum Disorder.
- The organization's academic collaborations continued with the addition of Dr. Steve Gentles, a postdoctoral research fellow to the Autism Ontario team for two years.
- Each Board meeting and meeting of the Management Team now includes an agenda item: Culture of Philanthropy Check-in. This is when we share stories and experiences related to our philanthropic activities on behalf of Autism Ontario. This can include personal calls or sending thank you cards to donors, or educating the community about autism and Autism Ontario. ■



Families in your community need your help

You can help those families today. Please consider becoming a **monthly donor**. You can give 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 **monthly donor**:

- Contact Autism Ontario at 416-246-9592.
- Donate online at www.autismontario.com (click on the Donate button).
- Mail your cheque, payable to Autism Ontario, to 004 - 1179 Street West, Toronto, ON M6K 3C5.

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



Visit our website: www.autismontario.com to view back issues of our magazine.

BMO Supports Autism Ontario's Adult Services Programs

PARTNERING FOR A MORE INCLUSIVE COMMUNITY

by Monica Richardson, Fund Development Manager, Autism Ontario

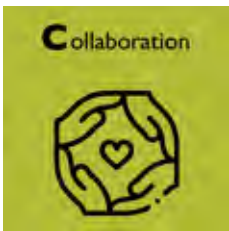
Autism Ontario is grateful for the commitment and leadership that BMO has demonstrated with this pledge, to finding solutions and innovative ideas to support adults on the spectrum across Ontario.

BMO HAS BEEN A COMMITTED PARTNER of Autism Ontario for many years, a recent sponsor of our annual golf tournament, and actively engaged with our World Autism Awareness Day flag-raising and community awareness campaigns. This year, they have pledged \$250,000 over five years to support our adult work.

The funding supports Autism Ontario's work with the York ASD Partnership, where we are working with the different service providers in the region to build upon the transition to adulthood programs that are currently in place. Because of this funding, we have been able to engage Dr. Vivian Lee, a Post-Doctoral researcher at York University's Developmental Disabilities and Mental Health Lab, who will collaborate with the York Region Chapter and the York ASD Partnership and will streamline and evaluate current programs being offered, while developing a more robust program plan for the region.

"BMO is committed to creating a society with zero barriers to inclusion, and investing in organizations that advocate for equitable opportunities and offer support for the communities we serve is core to our Purpose," said Nada Ristich, Head, Community Giving, BMO Financial Group. "We value the important work of Autism Ontario's critical Adult Transitions Program and are proud to partner with them to build a more inclusive community for autistic adults."

In 2019, Autism Ontario worked alongside three staff from York Support Services Network, an autistic self-advocate from York Region, and a social worker to adapt the "Living Life to the Full" course facilitator notes to support adults on the spectrum. As a result, we were able to not only produce an adaptation of this course delivery which uses group Cognitive Behavioural Therapy (CBT) for use by Ontario facilitators in Ontario, but also Canada. Additionally, we trained staff from York Support Services Network, Developmental Services Ontario York Region and Kerry's Place Autism Services to facilitate "Living Life to the Full" groups in the region for transition-aged youth and adults on the spectrum, as well as for caregivers. To date, four courses have been delivered, including one in partnership with Community Living in York Region, with more expected. ■



Book Review

Start Here

A Parent's Guide to Helping Children and Teens through Mental Health Challenges

by Pier Bryden MD and Peter Szatmari, MD

by Ola Kuzinerz, Webinar and Service Navigation Support Specialist, Autism Ontario

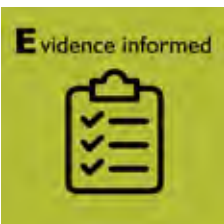


I HAVE OFTEN HEARD caregivers say that when their child or teen receives a formal mental health diagnosis, feelings of relief and confusion go hand in hand. There is a sense of relief because there is finally an answer to the many questions and concerns. At the same time, there is a feeling of panic; what does it all mean? What are the next steps? Who to connect with? Where to start? Doctors Pier Bryden, MD and Peter Szatmari, MD have combined their many years of medical expertise, knowledge and personal experiences to develop an easy-to-follow guide on where to start following a mental health diagnosis.

Start Here defines the many mental health illnesses that affect children and teens. Each chapter is dedicated to a specific illness and provides the reader with vignettes, definitions and a breakdown of supports and therapies specific to each illness. The book provides the reader with practical information including 11 pages of resources and a 10-page glossary, which provides clear definitions to the acronyms commonly used within the mental health field.

This mental health guide offers helpful resources and provides a sense of support and understanding, leaving the reader feeling more resilient. There are two main messages that resonate throughout the book: do not look away, and know that you are not alone. Both Dr. Bryden and Dr. Szatmari acknowledge that when faced with mental health illness, there is often a tendency to want to look away, to shut it all out. The doctors write, however, that parents should not ignore the signs of mental illness, and they encourage parents to face the difficulties straight on and seek the support that will allow their child or teen to learn how to live with their mental health illness. Bryden and Szatmari recognize that this can be a difficult process, and they want caregivers to know that they are not alone; there are other families in most communities going through similar circumstances as mental health illness affects many children and teens within our society.

Start Here: A Parent's Guide to Helping Children and Teens through Mental Health Challenges, is filled with helpful resources and relatable stories. The authors explain and define mental illness in an easily digestible way that allows both caregivers and professionals to understand what potential next steps to take following a formal mental health diagnosis. Dr. Bryden and Dr. Szatmari have developed a useful, current resource that I would highly recommend for both caregivers and professionals. ■



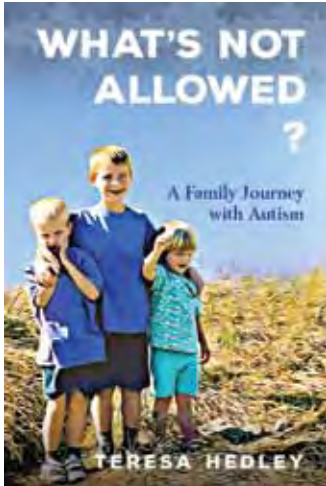
For more information on the book and where to order a copy following the links below.

Where to purchase the book: <https://www.simonandschuster.ca/books/Start-Here/Pier-Bryden-M-D/9781508257929>

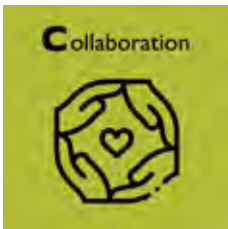
Landing Page with Resources: <https://content.simonandschuster.ca/start-here-a-parents-guide/>



Book Review



by Telah Morrison, Colonel, OMM, CD,
Director Military Family Service, Canadian
Armed Forces; Ottawa, ON



What's Not Allowed? A Family Journey with Autism

by Teresa Hedley

TERESA'S HEARTFELT STORY about raising her son Erik is filled with loving anecdotes of the challenging and at times lighthearted moments parenting a child with special needs. Through her eyes, we glimpse into the mind of her son with autism and his fascination with the things that many of us don't even notice in our everyday lives. It is pure brilliance.

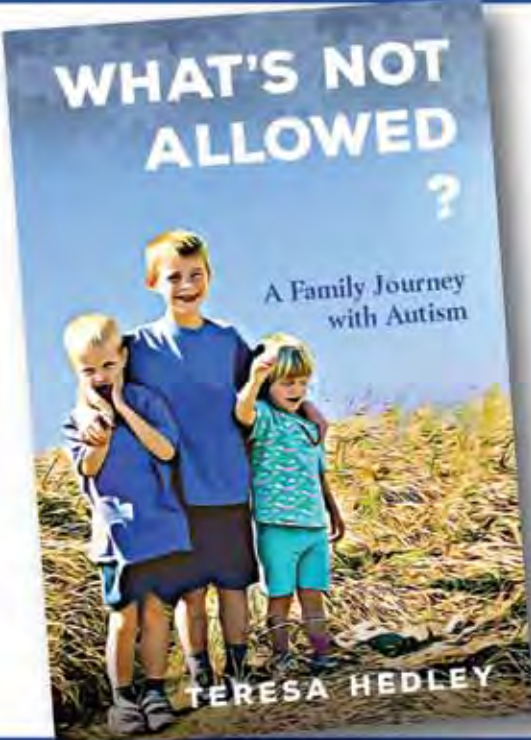
The Hedley journey portrays the myriad of challenges a military family must embrace on a posting, as well as packing up and moving, at times, to the other side of the country. To do so with a child with autism creates a new level of complexity.

Often funny, yet serious at its root, this book shows how it doesn't just take a village to raise a child: in Erik's case, it takes a small town. Supporters of Erik help Teresa see her child in a different light, for as a parent, one is perhaps too close to the forest to see the beautiful flowers in the trees.

Through the trials of high school, hormones and transition to adulthood, this story is a portrayal of how love and compassion overcome percentiles and projection. Teresa's strength to advocate for Erik helps ensure that the world can embrace his potential and help make him the extraordinary person he is.

At its core, *What's Not Allowed? A Family Journey with Autism* is a great story of hope, compassion and resilience. ■

CONNECTION | DIRECTION | ILLUMINATION | HOPE



"I highly recommend this book. Teresa is a gifted storyteller...overall a masterful blend of humour and authenticity."
—MIKE LAKE, Canadian Parliamentarian and international autism advocate; Edmonton, AB

"There are a lot of lessons on these pages for all of us, and we can benefit from considering them—and acting upon them."
—PETER MANSBRIDGE, former anchor and chief correspondent, CBC's *The National*; Stratford, ON

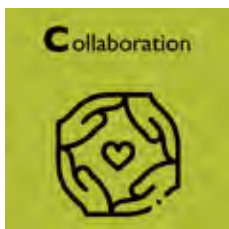
"A must-read for parents of children with autism, professionals and the general community."
—ELLEN YACK, occupational therapist, consultant, author and speaker; Toronto, ON

AVAILABLE ONLINE THROUGH CHAPTERS/INDIGO/COLES

In Your Corner

HIGHLIGHTING CHAPTER SUCCESSES, ACTIVITIES AND IDEAS. A SPACE DEDICATED TO SHARING, LEARNING AND FINDING WAYS TO SERVE OUR FAMILIES LOCALLY.

by Brittany Sherwood, Chapter and Volunteer Supervisor, Autism Ontario



▼ Some of the fun to be had this past fall in the Niagara Chapter with big grins from Eden Smith (left) and Maya Graham (right). Photos courtesy of Allyesa Stewart

OUR CHAPTERS HAVE BEEN BUSY this fall hosting virtual Annual Chapter Meetings to vote in new Chapter Leadership Council Members. We are so thankful for our volunteers and all the work they do to support Autism Ontario. Volunteers are at the core of our organization and we are always looking for more help. If you are looking for a way to give back locally, consider volunteering at the chapter nearest to you.

With COVID-19, we took a step back and made a few changes in our **Niagara Chapter**. The one thing we didn't want to change was the fun activities and programs we offered to families across Niagara. Over the past few months, we have learned and adapted to the world of virtual and at-home activities. We offered seven weeks of "Summer Camp in a Box," and to date have put together three recurring at-home digital programs (family trivia nights, virtual games night, and teen hangouts) as well as offering 13 at-home activity kits, ranging from make your own pizza kits, to DIY slime kits, planting kits and much more. While we miss being able to see the families we support on a regular basis, we are so happy to be able to continue to serve Niagara through these challenging times.



Our **Durham Chapter** kept families engaged by hosting virtual bingo calls and a painting party for parents.

The **Simcoe Chapter** was able to run a virtual “Kids Club” for children on the autism spectrum thanks to our generous donors. This program was a partnership with Wild Life Fitness and offered families in Simcoe County the opportunity to participate in some dancing, fitness, crafts and socialization.

Especially during these times of uncertainty, it's been wonderful to be able to connect families in our community together through this program and allow children to participate in a non-competitive group activity. We look forward to continuing into the fall.

The **Thunder Bay Chapter** Adult Group enjoyed a virtual paint night class where they painted photos of the Sleeping Giant.

This year, the annual **Huron Perth Chapter** Walk went virtual. Families were able to enjoy a walk on any day in September and enjoy the outdoors while raising funds for the Chapter. The Chapter also held a virtual scavenger hunt in August. Families had a great time taking pictures of their adventures to try and complete a bingo card.

The **Central West Region** is excited to offer the Artful Moments: Youth Art Program, which will run for six weeks in the fall in conjunction with the Art Gallery of Hamilton (AGH). Artful Moments will encourage youth with autism from Central West aged 14 to 21 to explore the world of fine art through activities including discussion, drawing, painting, collage, sculpture and mixed media alongside live instructions. Art kits provided by the AGH will be delivered to each registrant. Look out for more programs like this across the Central West region coming soon for various age groups.

Our **York Region Chapter** was busy with weekly Zoom calls with LEADers teen group, Fitness Tuesdays and Thursday Game Nights. They have also hosted virtual special events such as dances, pumpkin carving and Toronto Zoo visits. Our Halloween Drive-Thru event at Willowgrove Education and Farm Centre tested visitors' luck with tricks and treats. The staff are busy planning for the holiday season and running in the Scotiabank Toronto Waterfront Marathon.

Families in our **Windsor-Essex Chapter** participated in a Chopped Challenge. Each family received a mystery basket of food to prepare a dish with and the challenge was to combine all the foods into a creative dish. Videos were submitted and judged for creativity, use of ingredients and plated presentation. ■



▲ Some of Simcoe Chapter's art. Photos courtesy of Tammy Marshall-Skrabeck

A notice to our Chapters: The Chapter Corner is your space to highlight your successes and share stories of how you're making a difference in your communities.

By contributing, you are:

- *Accessing thousands of families, professionals and agencies*
- *Providing ideas and insight to other Chapters for activities, programs and events*
- *Building a stronger community across Ontario*
- *Demonstrating what you've accomplished locally*
- *Creating opportunities for dialogue and increased information sharing*

To share your stories, please submit ideas and content to christa@autismontario.com.

Poem

The Town that Time Forgot



Unsplash.com/AndyHolmes

This ancient city by the sea was as powerful as you and me
 Settled by many souls, it lay at the base of a mountain side
 What was sacred ground can change, as nature holds secrets dark and strange
 Signs were there, seen as superstition and silly, the rumbles and sounds from deep within

Ordinary day, sky blue as sapphire and sailors with their boats by the shore
 Shudders and shakes struck the earth, as their mountain Vesuvius awoke from slumber
 Shocked people raced to find shelter as the sky turned from blue to black and air sucked away

The mountain unleashed its strength, a tsunami of fire, gas and ash

Surges raced towards the town, with speeds the likes of which had never been seen
 Survival was grim, as those who tried to flee only found their way is suicide
 Submerged by flames and smoke, the mighty town was now an empty shell
 The day that changed the world unseen, was known as 79 AD

Uncovered by man and revealed to the sun, it is a skeleton of a world lost to space and time

The signs that remain and the people that were slain, frozen but whispering their story

A tale of Pompeii, showing what happened to the town that time forgot

◀ Pompeii Archaeological Park, Pompeii, Italy

Written by Alanna (Ali) Wilson ■



Yes! I want to make a difference helping people on the autism spectrum.

Direct my donation to:

- Provincial Office
- My Chapter _____
- Wherever most needed

I would like to donate:

- \$25
- \$50
- \$100
- \$ _____

Enclosed is my cheque made payable to Autism Ontario

OR

I'd prefer to pay with my credit card. Please charge to:

- VISA
- MasterCard

Card Number: _____/_____/_____/_____

CVV Number: _____ Expiration: ____/____

Signature: _____

Name: _____

Address: _____

City: _____

Prov: _____ Postal code: _____

Phone Number: _____

Email Address: _____



Please send this completed form with your donation to Autism Ontario

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

Incorporated as Autism Ontario
 Charitable Registration #11924 8789R R0001

From all the families, volunteers and staff at Autism Ontario, thank you!



Are you looking for an autism-related service?

Vous cherchez un service en matière d'autisme?

The Autism Service Listing (NEW)

The Autism Service Listing, hosted and monitored by Autism Ontario, is a one-stop-shop where people across Ontario can search for any autism-related service for themselves and their children. The list includes: mental health professionals, physiotherapists and occupational therapists, dentists and dental hygienists, physicians, speech language pathologists and audiologists, and more!

**[autismontario.com/
autism-service-listing](https://autismontario.com/autism-service-listing)**

Répertoire des services en matière d'autisme (NOUVEAU)

Hébergé et surveillé par Autisme Ontario, Le Répertoire des services en matière d'autisme est guichet unique où les gens de partout en Ontario pourront chercher, pour eux-mêmes ou pour leurs enfants, des services liés à l'autisme. Le Répertoire comprend : les professionnels de la santé mentale, les physiothérapeutes et ergothérapeutes, les dentistes et hygiénistes dentaires, les médecins, les orthophonistes et audiologistes, et plus!

autismontario.com/fr/repertoire-des-services-en-matiere-dautisme

The OAP Provider List

The OAP Provider List, hosted and monitored by Autism Ontario, is an online listing of clinical supervisors of Applied Behaviour Analysis (ABA) for children and youth on the autism spectrum. It is a resource Ontario families can use as they search for, select and confirm the qualifications of clinical supervisors who oversee the delivery of behavioural services.

On April 1, 2021 the OAP Provider List will become mandatory for all Clinical Supervisors who wish to provide behavioural services funded through the OAP.

oaproviderlist.ca

Liste des fournisseurs du POSA

Hébergée et surveillée par Autisme Ontario, la Liste des fournisseurs du POSA est une liste en ligne, dûment vérifiée, de superviseurs cliniques de services comportementaux pour les enfants et les jeunes autistes. C'est une ressource que les familles ontariennes peuvent utiliser lorsqu'elles cherchent et choisissent des superviseurs cliniques qui surveillent la prestation des services comportementaux et pour confirmer les qualifications de ces derniers.

Le 1er avril 2021, l'utilisation de la Liste des fournisseurs du POSA deviendra obligatoire pour tous les superviseurs cliniques qui souhaitent fournir des services comportementaux financés par le POSA.

oaproviderlist.ca/fr

HAS YOUR ADDRESS CHANGED?

Send your old mailing label and your new address to: Autism Ontario, at the address below.

PUBLICATIONS MAIL AGREEMENT # 40910519

CUSTOMER # 1012283

RETURN UNDELIVERABLE CANADIAN ADDRESSES TO:

AutismONTARIO

1179 King Street West, Suite 004
Toronto, ON M6K 3C5