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MATTERS

CARING AND
EVIDENCE-INFORMED

Pages 18 - 24

Info Autisme



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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.

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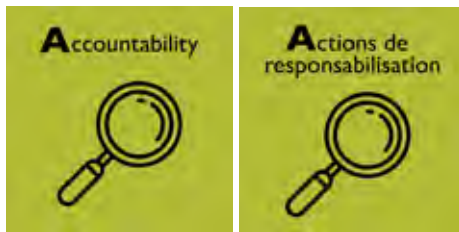
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Front cover: Connor McCurdy at age 11.

Photo credit: Jan McCrea

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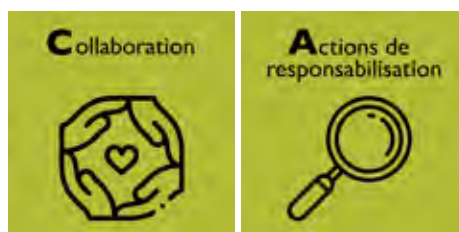
Autism Ontario's Values: CARE

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.



Listening

À l'écoute!

AUTISM ONTARIO aims to support and advocate for all autistic individuals across the province, regardless of race, ethnicity, income, religion or gender identity. The recent harrowing events remind us of the systemic injustices that have always and continue to exist for many of our marginalized members of society. These deep-rooted barriers are especially amplified for people who are Black, Indigenous and People of Colour. Along with the obstacles people on the autism spectrum may face, Black and Indigenous autistic people and their communities also struggle to acquire equitable access to education, employment, healthcare, housing and justice.

Now more than ever, we must be active and deliberate in listening to and including all autistic voices across the province. We will continue to expand our reach to neglected segments of our community. We will work to provide spaces of support and advocacy for our Black and Indigenous communities. And we will work together to dismantle the systems of oppression that prevent many autistic individuals from realizing their potential and living meaningful lives.

Now more than ever, we must be active and deliberate in listening to and including black autistic voices across the province. In keeping with this spirit, we invite you to pay special attention to *Racism in America Canada*, by Jessica Bethel on page 28. ■

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.

AUTISME ONTARIO vise à aider et à défendre toutes les personnes autistes de la province, peu importe leur race, leur ethnie, leur revenu, leurs convictions religieuses et leur identité de genre. Les récents événements nous rappellent que les injustices systémiques n'ont jamais cessé pour les membres marginalisés de la société.

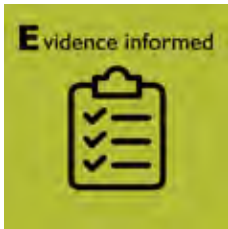
Ces barrières enracinées profondément dans notre culture sont ressenties de manière amplifiée par les personnes noires, autochtones et de couleur. En plus des difficultés auxquelles sont confrontées les personnes ayant un TSA, celles issues de communautés noires ou autochtones peinent également à obtenir un accès équitable à des services d'éducation, d'emploi, de santé, de logement et de justice.

Maintenant plus que jamais, nous devons agir; il faut écouter et inclure les personnes autistes de la province. Nous continuerons d'élargir notre portée pour rejoindre les groupes négligés de notre communauté. Nous travaillerons fort pour offrir des endroits dédiés au soutien et à la défense de nos communautés noires et autochtones. De plus, nous nous serrerons les coudes pour démanteler les systèmes d'oppression qui empêchent plusieurs personnes autistes de réaliser leur potentiel et de vivre une vie épanouissante.

Maintenant plus que jamais, nous devons agir; il faut écouter et inclure les personnes noires autistes de la province. Dans cet esprit, nous vous invitons à porter une attention particulière sur *le racisme au Canada*, par Jessica Bethel à la page 28 (en anglais). ■

Facing COVID-19 Together

SIX MONTHS AGO, HARDLY ANYONE HAD HEARD OF IT.



NOW, COVID-19 IS ALL THAT SEEMS TO MATTER.

With the world on lockdown, life has changed for children and adults with autism, their families, and their caregivers and supporters. In March 2020, as the virus began its global spread, Autism Ontario sent out a three-item questionnaire:

1. How can Autism Ontario best stay connected with you at this time?
2. Share your ideas of online resources we can create and share.
3. Are there particular needs or challenges you foresee?

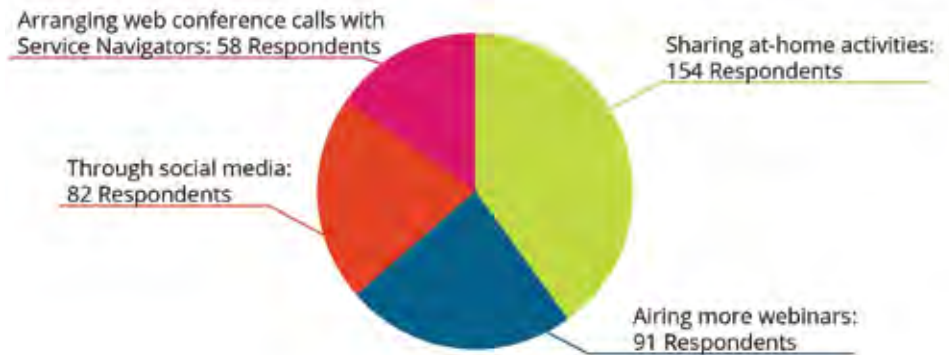
We shared it in both English and French and received 182 responses. The survey *Supporting Our Communities, April 2020* is the result of our careful listening to the autism community in Ontario. Its findings are being used to shape and guide how we reach out and support our families during the pandemic.

The first question we asked was, “How can Autism Ontario best stay connected with you at this time?”

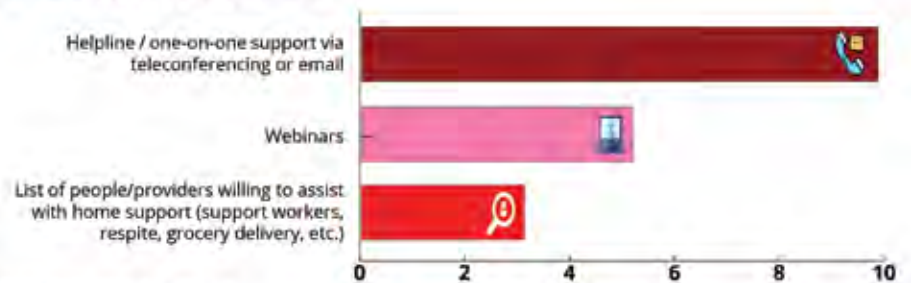
The majority of respondents to this question favoured more at-home activities, such as those that could be shared by family members. A smaller group of respondents asked for more webinars, while other groups asked for more communications through social media and web conferences with Service Navigators.

In the second question we asked what resources you needed. Your suggestions ranged widely yet seemed to fall into three categories: online support for parents, activities and resources, and support for general needs.

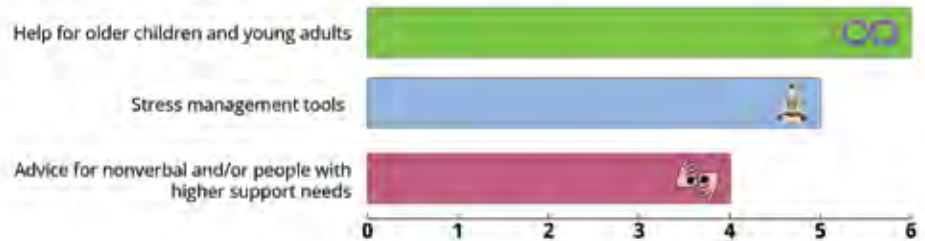
The third question we asked was about challenges and opportunities that you foresaw over the next few months. Some respondents focused on the stress



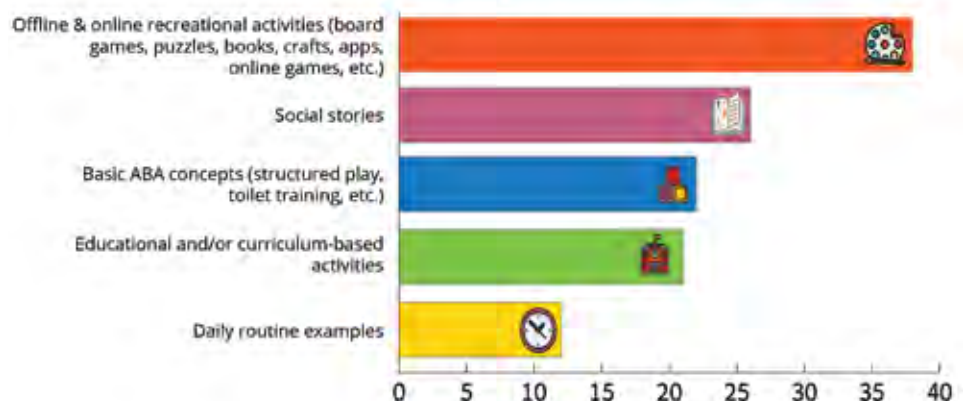
Online Support for Parents

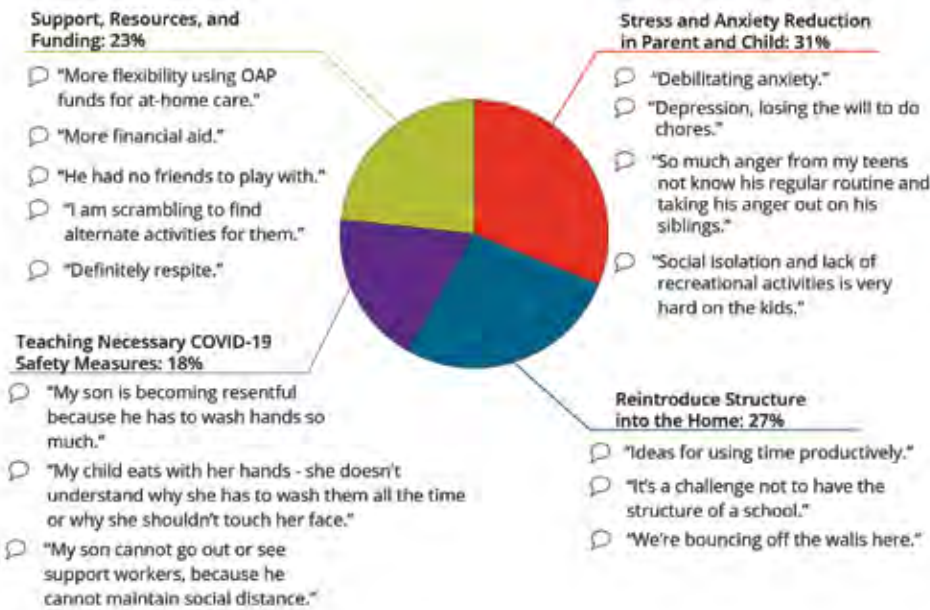


More General Needs



Activities & Resources for Autistic People and their Families





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.

and anxiety they and their families faced. Other respondents discussed the need to reintroduce structure into their homes, while others discussed the need for social stories that would help families discuss necessary pandemic safety measures.

To all our respondents, thank you so much for taking the time to share your experience, ideas and concerns. It has been incredibly helpful. We will continue to listen and to craft useful resources; meanwhile, here are some offerings from Autism Ontario that address issues the survey raised:

- A list of online, at-home activities suitable for families. We have also provided hands-on family activities, including pizza-making and donut-making.
- A series of webinars, hosted by experts in their fields, with topics ranging from Employment Readiness (geared for teens and young adults on the spectrum) to Wellness and Self Care.
- Service Navigators, available by phone or by video conference, to provide that valuable link in our community, connecting families to services.
- Frequent information updates on our website and social media channels.

This is the result of the efforts of staff and volunteers working in new and creative ways, ensuring that we can support people with autism and their families across Ontario with meaningful and productive activities. Your assistance will help us as we continue to look for innovative ways to support the autism community in the new normal.

Please donate today at www.autismontario.com, or by calling our Gift and Membership Coordinator at 416-246-9592, or by placing your donation in the enclosed self-addressed postage-paid envelope. With your financial support, you can make a real difference in the lives of more than 135,000 Ontarians and their families affected by autism. We need your help more than ever! ■

Coping with COVID-19

AN ASPERGIRL AND HER FAMILY

by Courtney Weaver, Self Advocate

Coping with COVID-19 has resulted in positive and not-so-positive changes for “the Weaver Crew,” my sisters Ashley and Serena, my mom Rebecca, dad John, and me.



I MISS PERSON-TO-PERSON INTERACTION at work and in office spaces as well as activities like going to the movies and the gym. However, doing work from home, interspersed with walks when there are minimal people around, has added more structure to my and my roommate’s 24/7 home life. I am very concerned about my future as only essential businesses are currently open and one of my two jobs is scheduled to end in May. I continue in my other job and look for more work. Meanwhile, employment insurance and emergency benefits are viable options to successfully make it—hopefully.

Serena misses seeing me as we are living in different parts of Ottawa and are following the official guidelines of isolation. She had the final months of her undergraduate experience at Brock University cut short when classes and exams were moved online and all university rowing events and practices were cancelled. Given this change, there was no point remaining in St. Catharines so she moved back to Ottawa early. Her June convocation has been cancelled which disappointed her. She is also concerned about finding summer work due to the current limited job opportunities.

Ashley has been laid off from her job at Tim Horton’s and is praying every day for the pandemic to be over. She misses being able to see her friends and fiancé. However, she does not mind being in the house all the time. My parents ensure she gets out for some fresh air every couple of days with family walks. She is spending



Courtney Weaver ►



less time on the computer and iPad and is diversifying her at-home activities, such as doing puzzles and word searches.

Rebecca misses the office atmosphere of her job and the person-to-person interaction. However, she enjoys getting to decide when to work during the day and not having to dress formally, and is surprised at how well working from home is going. She loves being able to do workouts in the afternoon with Serena and the increased and relaxed family life she has, now that there is no travelling to and from work or other activities, such as volleyball and gym. She has also observed how hard-hit the world is by the pandemic and how everyone is stressed and overwhelmed with the change in their lives (getting laid off from work, for example) and routines. As such changes are always a struggle for people with ASD traits, Rebecca hopes that this will increase empathy for families of children

on the spectrum not having school or therapy to go to.

Finally, John has been mixing time between the work office and home because he is critical staff. There is an increased demand from people wanting to know what the Canadian government department he works for is doing. He's noticed that his colleagues are getting better at understanding the new norms of working from home, including using video conferencing services such as Zoom and Web X. He has also noticed a decrease in gas prices and traffic and a communal increase in family time and walks. At home, he is also doing online exercise programs, or ones set by Serena, to stay fit. He loves the additional family time that is resulting from staying home more. Both he and Rebecca are doing several things to look after John's very elderly parents, including constant phone calls and grocery shopping.

Living and coping with the global effects of COVID-19 has mixed results. We all hope for more businesses to open and job and leisure opportunities to increase. However, it would not be good to lose the positive effects of the family bonding that has resulted from not having as full a personal schedule. Finally, important life and global lessons regarding personal hygiene, disease transmission, and how fast-paced society has become have to be taken into consideration going forward for personal betterment and for the world to be better equipped should something like this happen again. ■

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 **Autism**MATTERS 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

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Where are Mom and Dad?

HOW OUR SOCIAL DISTANCING CAN BRING FAMILIES TOGETHER SOONER

by Monica Richardson, Fund Development Manager, Autism Ontario



MARCH 24 WAS OUR SON'S 27TH BIRTHDAY.

We ventured to Matthew's home with a birthday cake his sister had baked, and while there were not yet official isolation rules in place, we kept a respectable distance from the personal support workers and staff at his group home. Little did we know that it would be weeks, possibly months, before we would be able to kiss him, hug him, or have our Friday "date night" at Swiss Chalet again.

Our son has autism. He is non-verbal and requires 24/7 care. Matthew requires considerable supports but has an incredible "filing cabinet" memory—he knows where his favourite restaurants are and uses pointing, sounds and visual cues to communicate.

He also knows that life has changed for him. Mom and Dad no longer come around on Friday to take him to our local Swiss Chalet, where the staff know our family and all our orders. No more Sunday night visits home where Matthew remembers where all his favourite foods are in the house. No more walks or car rides. No more gym workouts with his awesome trainer, Daniel.

And he doesn't know why this has happened.

We have FaceTimed with Matthew a few times, but while he can see us and hear us, the look of puzzlement on his face tells us he doesn't really understand this. After weeks of this new way of interacting, he has started to smile and touch the phone in his way of saying hi or bye. His team has been incredibly supportive and creative in finding ways to keep Matthew and his housemates engaged and busy, avoid harmful or aggressive behaviours, and practice lots of hand washing, cleaning and sanitizing.

Social isolation has been hard for everyone, and for us and Matthew. It's turned our world upside down. We're worried about how much longer this will go on, when we can visit in person or get back to our Friday date nights. Even when we do, those dinners at Swiss Chalet may be still be different.

People talk about the silver lining in all of this. For Matthew, especially, I wonder what that is.

This pandemic has made one thing crystal clear: our health and the love we have for our family are the most important things. It is also the reason we have been practicing physical distancing, to protect those we love, particularly the elderly and vulnerable. We all need someone to love. We all need life to return to normal, whatever that normal looks like—and soon, especially people with autism and other developmental disabilities. So, please keep washing your hands and practicing distancing for just a bit longer. We, and other parents like us, will be so grateful. ■



Photos: (Top) Matthew on his 27th birthday
(Below) Matthew and his mom, Monica





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Writing Social Narratives

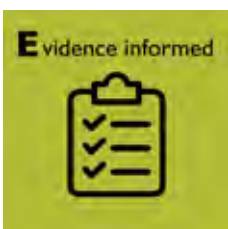
WE ARE ALL BY NATURE STORYTELLERS

by Michael Cnudde, Communications Specialist, Autism Ontario

WHETHER IT'S AROUND A CAMPFIRE, snuggled into bed with your child and a good book or, more recently, through video conferencing link, the desire to tell stories that both communicate and explain is as old as the human race. Social narratives are very much in this tradition. They are an evidence-informed method of providing structured direction on a given subject to people on the autism spectrum.

In constructing a social narrative, determine what it is you want to communicate. Let's say that you'd like your child to develop a self-care skill such as washing their hands. You want to show your child how to wash their hands and explain why it is necessary, as well. Your first step should be to gather information. It's helpful to think of questions you need to answer: *Who's* involved? *What's* involved? *When* does it occur? *Where* does it take place? *Why* is it important? *How* does it affect me and others around me?

Once you have all the details you need, it's time to shape your narrative. Like all good storytellers, you need to remember your audience and craft your sentences accordingly. In general, though, it's best to avoid overtly prescriptive terms like *don't* or *never*. If you are talking about an outcome that can't be guaranteed, use terms like *sometimes* or *usually*.



Wherever you can, use description rather than directions. Set the scene with a situation and people that your child can relate to and include descriptions of your child's feelings and responses. Directive sentences are necessary, as they help to provide guidance. A recommended ratio of descriptive to directive sentences is 2:1. Review your narrative with your child before and after you introduce it to them; going over it with your child a few weeks later allows you to see if it is working for them.

A social narrative about hand-washing might look like this:

- Everybody washes their hands after they go to the washroom or before they eat.
- Washing hands helps keep things clean and stops people from getting sick.
- After I go to the washroom or before I eat, I will wash my hands.
- I will use soap and warm water and count to 20 while I wash my hands.
- Sometimes the water may be too warm, but that's okay.
- When people are done washing their hands, they dry them with a towel and hang the towel up.
- When I am finished I will turn off the taps and dry off my hands with a towel and will hang the towel back up.

To give another example, a social narrative regarding going back to school might look like this:

- In September, all students will go back to school.
- I will be in Grade 5 at Breaburn Public School.

- My teacher will be Ms. Singh.
- It will be different from before, but that is okay.
- I may be nervous or upset, but that is okay.
- If I feel nervous or upset, I will ask my teacher for help.
- Everyone at school keeps their hands to themselves.
- I will keep my hands to myself.

Depending on the need or occasion, you may also wish to use pictures to illustrate your social narrative. These can come from a variety of sources, such as old magazines or the internet. You may also wish to create a simple comic strip, which has the advantage of both dialogue and thought bubbles, so that you can relate not only what other people say and do, but also what they also may be thinking. A comic strip format like this can be useful to many autistic people who may not readily pick up on social cues.

There are a variety of apps, software and other online resources available that you may find useful. Here are a few by way of example (not recommendation):

- Picto-selector, free to download for Mac OS or Windows, can be used to create visual schedules and social narratives: <https://www.pictoselector.eu/>
- Connectability.ca has a free online Visuals Engine that can be used to create social narratives: <https://connectability.ca/visuals-engine/>
- MagnusCards is a free app for your smartphone that combines social narrative with game design: <https://www2.magnusmode.com/>

- Strip Designer is an app that allows you to take photos, orient them in a comic-strip fashion and add dialogue and thought bubbles to create your social narrative: <https://apps.apple.com/ca/app/strip-designer/id314780738>
- Boardmaker provides software and symbols that can be used to customize photos for your social narrative: <https://goboardmaker.com/pages/boardmaker-online>. It offers some free resources, including a 60 day trial: <https://goboardmaker.com/pages/coronavirus-resources>

Social narratives can be used in a variety of situations—at home, in the classroom and at the workplace. They can be used to celebrate accomplishments, as well. ■

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- Social Stories*, <https://autismcanada.org/living-with-autism/treatments/non-medical/communication/social-stories/>

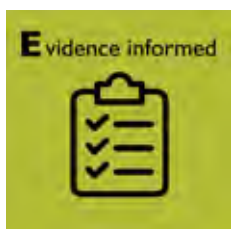


Autism Ontario flag in Red Willow Public School's display case

Caring and Evidence-Informed

WELCOME TO MS. MACDONALD'S CLASS

by Michael Cnudde, Communications Specialist, Autism Ontario



NESTLED IN THE SPRAWLING SUBURBS of northeastern Brampton, about 30 minutes north of Toronto, is Red Willow Public School. In her first-floor classroom, teacher Carole Ann MacDonald supervises her class of six children on the autism spectrum, who are in Grades, 3, 4 and 5.

Despite the small size, the classroom is busy this morning, an example of caring in action. Carole Ann, who is also on the spectrum, guides her students through calendar time with the help of her two educational assistants. “The students cannot fool me; I can tell the difference between behaviour and ability,” she says.

A typical day, says Carole Ann, can be filled with academics, meltdowns and all subjects in the curriculum. “We don’t exclude any Ontario curriculum subject from IEPs (Individual Education Plans),” she points out with pride. “We individualize and



Carole Ann MacDonald

customize but not at the cost of excluding subjects.”

Important to her is that her school actively supports the goal of autistic acceptance. Red Willow participates in Autism Ontario’s annual Raise the Flag ceremonies and the Autism Ontario flag has a place of pride in the school display case, along with the sports trophies in the other cases in the front lobby.

With 15 years’ experience as a teacher, Carole Ann says she feels well-supported by her colleagues, including her principal Saira Salman and superintendent Patrika Daws. Best of all is that Carole Ann has direct, in-person access to professionals. “A teacher can’t wear every hat—psychologist, social worker, speech language pathologist. When these professionals offer advice on improving, I am the first teacher to incorporate it.” Carole Ann embraces any extra help. When technology teacher Heather Hughes arrives in the classroom, part of her role is to teach the teacher.

It’s now time for bringing out the classroom’s electronic whiteboard. One of the educational assistants uses it to show a short educational video.

Carole Ann has other resources available to her and her students as well: for example, laptops and access to a school sensory room. This room, designed with the help of an occupational therapist and paid for by the school budget and extra fundraising, is another example of the evidence-informed approach Carole Ann takes to teaching children on the spectrum. It’s a quiet place furnished with plenty of cushions, soft toys, low lighting and bubble tubes that provides students with a place to go when they become overstimulated. “They can relax or if they need to have a meltdown they can go and have it there safely and with dignity,” says Carole Ann.

Carole Ann says she was motivated to become a teacher because the skills involved in teaching were transferrable to parenting. Carole Ann’s daughter, Brooke Magel, is now 24 and a graduate student at York University. Through the process of raising her daughter, who is not on the spectrum, Carole Ann began to identify with the needs of parents who might be challenged in any number of ways. Schools are not just about students, she says—they’re also about parents. “As a government institution we need

to remember to accommodate not only the students’ challenges but also those of their parents. That is equity!”

It’s the opportunity to see students thriving that drives Carole Ann the most. “Students get intensive support over two to three years in this contained ASD program,” she says. “After their time here they leave at or close to their grade level. That’s the whole idea behind this ASD program.” She smiles as she remembers one of her early students. “I have one student I taught, he recently graduated from University of Waterloo with a degree in mathematics. He is a huge success story for the Peel District School Board and that is what keeps me motivated each and every day. I know that what we are doing as a team is working.” ■



Learning DOT AutismONTARIO

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Autism Ontario's free Education Portal is a one-stop shop for helpful autism-related resources. Once you register, you will have access to all past webinars, helpful articles, and information about Autism Spectrum Disorder to assist you on your journey from diagnosis through to adulthood.

Webinars | Educational Events Calendar
 Archived Issues of *Autism Matters* Magazine
 Helpful Articles | and more...



The Art of Mindfulness

WE ARE ALL IN THIS SITUATION TOGETHER



by Stephanie Moeser, BSW, MSW, RSW

EACH OF OUR SITUATIONS are unique; some of us are finding it manageable and nice to slow down; some of us are finding it overwhelming and are juggling many different roles; some of us work in frontline health care or have family who work in health care; and some of us may have friends or family directly impacted by COVID-19. All these experiences can bring up a range of different emotions, thoughts and even physical sensations. There is no right or wrong way to feel. We have no roadmap and even if we did, each person's journey would be completely different. A helpful tool can be our own moment-to-moment awareness, without judgment and with compassion. We can't do this wrong. All our feelings are valid. Essentially, this moment-to-moment awareness without judgement is mindfulness.

When the term *mindfulness* comes up, many people automatically think of meditation. Formal meditation and mindfulness are not the same thing. When people think of meditation, they often think of clearing the mind. Of non-worry. Of peacefulness. Of some sort of elusive experience of spiritual bliss. Perhaps this is true for monks who for many years, practice daily. Let's be clear, this is a noble and faith-filled path but it is not what most people attain. Nor should it be the goal. In fact, in mindfulness, striving for a specific feeling or experience is the exact opposite of mindfulness.

Photos.com

An oft-quoted Kabat-Zinn, and the definition of mindfulness that I turn to the most, is this:

“Mindfulness means paying attention in a particular way, in the present moment, and non-judgmentally.”

Let’s take a moment to break that down. That doesn’t sound anything like striving for some sort of stillness or inner peace. If it was only so easy to think your way to peace and stillness. The “try harder” approach to a quiet mind and less worry is a recipe for frustration and in fact, more worry.

Mindfulness is acceptance

I understand that accepting the present state of things and our reactions around it, is difficult. We want things to go back to how they were and if they can’t go back to how they were right now, we want to know WHEN. When will the old normal return? Will the new normal

look like the old normal? How much longer can I do this? How much longer will my kids be without in-class teaching, with anyone but me being their teacher? When will they be back to programs and therapy and swimming lessons? When can they swing on swings in the local playground again?

Mindfulness is allowing space and purposeful intention for feelings to be what they are

To feel them. To experience them. To not hold on to them. To experience them, as an observer and then to let them go. You are experiencing the emotions and sensations. You are *not* the emotions and sensations. That difference may seem minimal, but in fact, it is major. That shift is significant. Allow yourself that pause. Allow yourself to know whatever rises and whatever you are feeling is okay, even if in the moment it doesn’t

feel okay.

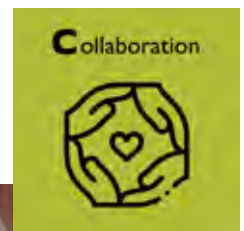
If the idea of allowing yourself to experience all these emotions and sensations seems too much, that’s okay. In those moments, pick something to do that can distract you. Something you can put your intention and attention to. This could be putting together Lego with your child, baking, getting a garden ready, listening to music (really listening), doing dishes by hand, doing yoga, or going for a socially distanced walk... Essentially, find something to do that centres you, even if just for a few moments.

Remember that you can’t do this wrong

This is a new experience for all of us. But the one thing I’d like everyone to try a bit more, is to remember to turn compassion inwards. To shed some positive light on yourself. ■

It’s Doughnut Time!

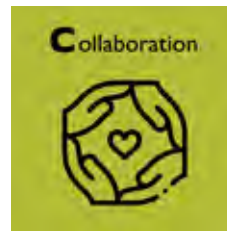
AUTISM ONTARIO’S latest family baking event was a big success for everyone involved. Here are (from L-R): Andres Martinez, Trevor Leach and Rachel Hazelwood, as they participated in the doughy fun. A big shout out, too, to our Service Navigators for helping make it possible! ■



Raising the Flag

THURSDAY, APRIL 2, 2020 marked World Autism Awareness Day. While COVID-19 may have changed how we celebrated the event, it did not change its significance: highlighting the progress of the autism community in Ontario and around the globe.

Our determination to mark the occasion was not dampened. Instead of gathering together to celebrate across the province, we encouraged our friends to engage in their own Raise the Flag activities at home. One activity we suggested was a colouring contest—and what a response we got! Here is just a sample of your incredibly creative artwork. Thank you to everyone who submitted. ■

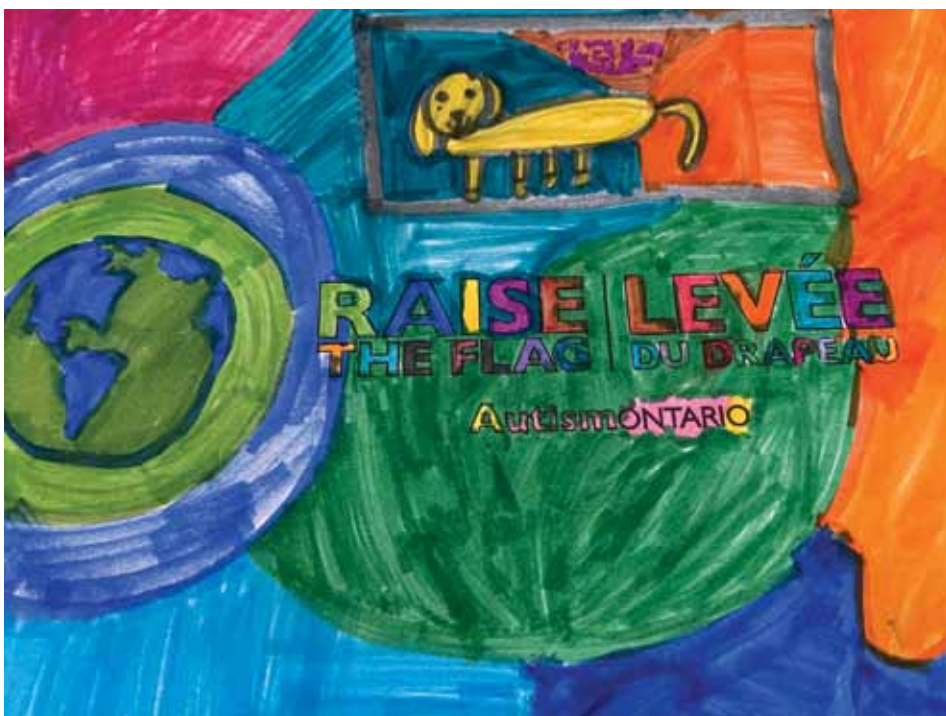


Hunter S. ▶

◀ Desmond H.

Sophie P. (lower left)

Samantha ▼





◀ Jillian D.



Lucan ▶



Tobias M. ▶



▲ Victoria R.



Zemira ▶

INFO Autisme



L'appui continue dans le Nord-Est

par Angèle Paquette, prestataire des services de navigation, région du Nord-Est, Autisme Ontario

LES RESTRICTIONS IMPOSÉES par la COVID-19 n'ont pas changé notre engagement envers les familles touchées par l'autisme. Elles nous ont amené à examiner d'autres façons de soutenir nos familles, et nos efforts ont porté fruit. Les services de navigation partout en province misent sur les activités en ligne, en anglais comme en français. Les parents peuvent participer aux ateliers et aux séances d'information sur le Programme ontarien des services en matière d'autisme (POSA) dans le confort de leur foyer, via la plateforme Zoom. De plus, les familles peuvent bénéficier des diverses trousses (bricolage, peinture, cuisine, plantation, construction, etc.) offertes partout en province grâce aux partenariats noués avec les entreprises locales.

Deux activités offertes dans le Nord-Est ont été bien appréciées des familles. À North Bay, Greco's Pizza Algonquin a généreusement fait don de plus de soixante trousses de confection de pizza. Les familles n'avaient qu'à ramasser leur trousse en bordure de la rue. Quelle activité délicieuse! À Timmins, les familles ont pu recevoir des trousses de décoration de petits gâteaux de Just Because, une boulangerie locale, tandis qu'un studio d'artisanat offrait des certificats-cadeaux pour l'achat de matériel de bricolage. Ces deux activités ont eu une popularité étonnante!

La planification d'activités continue. Au mois de juin, une psychothérapeute francophone de la région du Nord offrira un atelier de bien-être en ligne. De plus, les familles pourront s'inscrire pour recevoir des trousses de décoration de beignes dans la région du Nord-Est! ■

« Pendant le confinement, je danse devant la télé et je fais du sport avec maman. » Daisy – 5 ans

D'un enfant à l'autre!

par Suzanne Murphy, consultante pour les services en français, Autisme Ontario

ON PEUT TROUVER EN LIGNE une multitude de ressources liées à la COVID-19. Pour sa part, Autisme Ontario a rassemblé une panoplie de ressources pour la communauté de l'autisme, en français comme en anglais, et les a rendues disponibles sur son site. Une de ces ressources me touche particulièrement. Le réseau POND (Province of Ontario Neurodevelopmental Network) a créé une vidéo en anglais animée par des enfants pour les enfants. Autisme Ontario a alors saisi l'occasion de produire une version française de la vidéo avec des jeunes collaborateurs et collaboratrices francophones de différentes régions de la province. L'animateur présente ce qu'est le coronavirus, explique ce que les enfants doivent faire pour se protéger et propose diverses activités pour les enfants. Par la suite, d'autres enfants partagent ce qu'ils font pour s'occuper et garder une attitude positive. En les écoutant, on constate que chaque enfant fait face à cette situation de sa propre façon. Le produit final est la voix authentique d'appui d'un enfant à un autre en cette période de confinement. Merci de votre partage. Pour visionner la vidéo : <https://pond-network.ca/covid-19/>. ■

L'entente Canada-Ontario appuie le travail d'Autisme Ontario

par Suzanne Murphy, consultante pour les services en français, Autisme Ontario

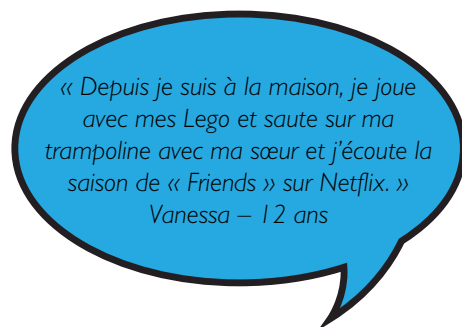
LE 21 OCTOBRE DERNIER, Autisme Ontario apprenait que des bourses lui étaient décernées dans le cadre de l'Entente Canada-Ontario pour les services en français.

De concert avec Patrimoine canadien, l'entente Canada-Ontario vise le développement et l'amélioration des services de qualité en français, ainsi que leur accessibilité pour la communauté francophone de l'Ontario, conformément aux obligations prescrites par la *Loi de 1986 sur les services en français*.

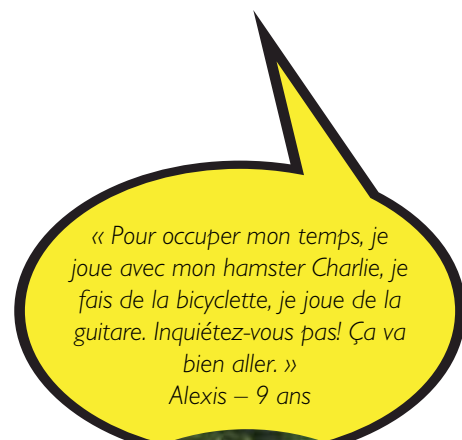
Ces bourses permettent à Autisme Ontario d'accroître ses ressources en français conçues pour venir appuyer davantage la communauté de l'autisme. Voici les ajouts apportés au portail éducatif grâce à ces fonds :

- Se rendre compte que son enfant est autiste : comprendre l'évolution des parents à participer aux soins;
- Problèmes de sommeil et troubles du spectre de l'autisme (TSA);
- La dynamique d'une famille de trois enfants, dont deux ayant un trouble du spectre de l'autisme, une série de quatre articles rédigés par Courtney Weaver;
- Une belle et courte vidéo qui, à l'aide d'histoires, solidifie les liens de la communauté de l'autisme.

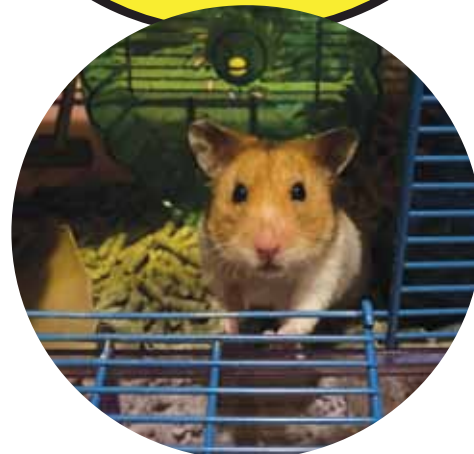
De plus, ces bourses ont permis la traduction de deux programmes, soit le programme CARES du SAAAC Autism Centre (South Asian Autism Awareness Centre) et le guide supplémentaire du programme *L'art de se faire des amis (Children's Friendship Training)*.



« Depuis je suis à la maison, je joue avec mes Lego et saute sur ma trampoline avec ma sœur et j'écoute la saison de « Friends » sur Netflix. »
Vanessa – 12 ans



« Pour occuper mon temps, je joue avec mon hamster Charlie, je fais de la bicyclette, je joue de la guitare. Inquiétez-vous pas! Ça va bien aller. »
Alexis – 9 ans



Crédit photo : Alexis



« Je danse des danses traditionnelles, je joue mon jeu préféré sur l'ordi, j'invente des chansons pendant ce temps de confinement »
Davina – 9 ans

CARES est un programme de soutien aux aidants naturels qui prend la forme d'une intervention de groupe innovante consacrée aux problèmes sociaux, émotionnels et psychologiques que peuvent affronter les personnes qui prennent soin d'enfants autistes. Ce programme offre un espace sûr où les aidants naturels peuvent partager leurs expériences et développer un sentiment d'identité commune.

Une formation virtuelle sur le programme *L'art de se faire des amis (Children's Friendship Training)* fut offerte grâce à un partenariat avec le Centre de ressources pour les familles des militaires de Trenton. Cette formation a donné lieu à la participation de membres du personnel scolaire, des fournisseurs de services et des centres de ressources pour les familles des militaires de différentes régions de la province. La traduction du guide supplémentaire permettra aux enfants francophones d'accéder à ce programme basé sur des données probantes.

Autisme Ontario apprécie l'appui offert par l'Entente Canada-Ontario et en est reconnaissant. La communauté francophone de l'autisme bénéficiera de ces nouvelles ressources pour des années à venir. ■



Crédit photo : Céleste Séguin

Une nouvelle expérience!

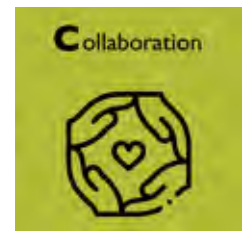
par Céleste Séguin, parent

GRÂCE À AUTISME ONTARIO et à la générosité des partenaires communautaires, nous avons pu profiter d'une belle activité en famille. Notre première expérience de plantation à la maison s'est avérée un vrai succès! Étant donné le nombre limité d'activités possibles en ce moment, c'était un vrai plaisir de faire quelque chose de différent.

Merci Valley Trees and Shrubs pour les troussees. ■

Dégustation délicieuse à Durham

par Miska Jones, prestataire des services de navigation, région de Durham, Autisme Ontario



LES FAMILLES D'AUTISME ONTARIO ont su s'adapter à la nouvelle normalité, en ce qui concerne les soutiens fournis pendant la pandémie. Les groupes de soutien et les ateliers auparavant offerts en personne sont passés au mode virtuel. Des séances sont prévues à divers moments de la journée, pour offrir une flexibilité maximum aux familles. Nos occasions d'apprentissage social se poursuivent, mais sous forme de troussees à emporter qui permettent la participation de toute la famille.

À Durham, une boulangerie locale a offert aux familles des troussees à décoration de petits gâteaux. La procédure est simple : inscription, ramassage sans contact, préparation en famille des petits gâteaux, et dégustation. Yum! ■



« Moi je joue au basketball avec mes deux frères et au Roadblocks avec ma sœur. »
Cohen – 6 ans

Grande popularité des troussees d'activités à domicile dans l'Est!

par Kelsey McDaniel, prestataire des services de navigation, régions de l'Est - Ottawa, Prescott-Russell, Stormont, Dundas et Glengarry, Autisme Ontario

« Je joue dans le Nintendo Switch avec mon papa et je regarde de la télévision. »
Andie – 7 ans

À OTTAWA, PRESCOTT-RUSSELL et Stormont, Dundas et Glengarry, nous continuons de faire profiter nos familles de diverses troussees d'activités à domicile. Depuis la mise en place des restrictions découlant de la pandémie de COVID-19, nous avons pu offrir à Ottawa, Cornwall, Rockland et Casselman un total de six troussees d'activités à domicile, portant notamment sur la peinture de poterie, la confection de pizza et la décoration de beignes. Les commentaires des familles sont très favorables et nous espérons continuer à organiser de nouvelles activités amusantes au cours des prochains mois.

« Mille mercis! Nous nous sommes vraiment amusés et régalez hier soir en préparant nos pizzas. Nos deux enfants se proclament maintenant les cuisiniers de la maison. » Trousse de Mr. Mozzarella - Nepean

« Un grand merci pour vos troussees de confection de pizza, qui nous ont fait passer un amusant et délicieux week-end! » - Ottawa

Outre nos troussees d'activités à domicile, nous avons organisé des groupes de soutien aux parents, des ateliers et des séances d'information sur le Programme ontarien de services en matière d'autisme. ■

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.

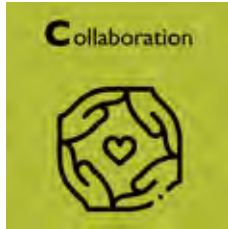
AutismONTARIO

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

Les membres d'Autisme Ontario reçoivent automatiquement cette revue.

Un soutien de grande portée

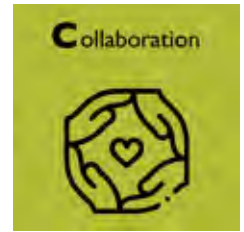
par Sinthea Chowdhury, prestataire des services de navigation - spécialiste en relations communautaires, Autisme Ontario



MALGRÉ LES FERMETURES de bureaux et les annulations d'activités, une constante est demeurée : le besoin indéfectible de soutenir et de maintenir le contact. Pendant cette période sans précédent, nous avons collaboré très étroitement avec nos partenaires des communautés autochtones afin de faire en sorte que les familles les plus vulnérables, partout en Ontario, aient accès aux ressources éducatives et récréatives pour leurs proches qui vivent avec l'autisme. Avec le constant soutien de Chiefs of Ontario (COO) et des dirigeants de la nation Nishnawbe Aski et grâce à la générosité des entreprises locales, nous avons offert aux familles des boîtes à curiosités et des trousseaux sensorielles qui ont été livrées à leur porte, en milieu rural comme en milieu urbain, de même que des codes de cinéma Cineplex dont elles ont pu profiter à la maison. Il s'agissait d'une initiative s'adressant exclusivement aux communautés autochtones, et avec l'aide de nos partenaires communautaires, le mot s'est rapidement propagé et nous avons pu rejoindre 85 familles autochtones de réserves autochtones nordiques aussi éloignées que Moosonee et Attawapiskat. Nous espérons que ce partenariat se poursuivra et nous donnera de nouvelles occasions de tisser des liens avec les familles autochtones et de forger de nouvelles relations avec les entreprises et les communautés locales. ■

Passer au travers de la pandémie avec résilience

par Kim McAlpine, prestataire des services de navigation, régions de Niagara, Haldimand, Norfolk, Brant et Oxford, Autisme Ontario



JE M'APPELLE KIM, et je suis la prestataire des services de navigation d'Autisme Ontario pour les régions de Niagara, Haldimand, Norfolk, Brant et Oxford.

Je travaille dans le domaine de l'autisme depuis près de 15 ans. Durant ce temps, comme thérapeute de première ligne, j'ai côtoyé de nombreux thérapeutes dévoués que j'ai vus se donner à fond dans tout ce qu'ils font. J'ai absolument adoré mon expérience de thérapeute, car je trouvais très enrichissant de travailler directement avec les familles. Par la suite, on m'a offert un poste très différent, qui me permettait de continuer à aider les familles mais selon une autre perspective. En tant que coordonnatrice du soutien aux familles, j'ai découvert que j'aimais beaucoup apporter un soutien direct aux familles, que ce soit pour les aider à revendiquer les droits de leur enfant ou à comprendre un système parfois déroutant. J'ai réalisé que ce nouveau rôle était tout aussi gratifiant que celui de thérapeute. J'avais trouvé ma vocation!

Il y a un an, j'ai postulé un poste de prestataire des services de navigation chez Autisme Ontario. Quelle chance pour moi d'avoir trouvé cette organisation! Depuis un an que je travaille pour Autisme Ontario, j'ai rencontré des collègues dévoués, attentionnés et authentiques dans tout ce qu'ils font pour les familles qu'ils aident. Je suis reconnaissante de pouvoir poursuivre le travail que j'adore, non seulement avec les familles avec lesquelles j'avais déjà tissé des liens, mais aussi avec les nombreuses familles que j'ai rencontrées en Ontario et avec les autres organismes et professionnels qui accomplissent au quotidien un travail incroyable.

Pour beaucoup de familles et pour les organisations qui ont pour vocation de les soutenir, la situation actuelle s'accompagne de certaines, voire de nombreuses complications. Cela dit, je suis étonnée et impressionnée de la rapidité avec laquelle ces organisations ont relevé le défi et trouvé des moyens de continuer d'appuyer leurs familles partout en Ontario.

Autisme Ontario redouble d'imagination pour continuer d'accompagner les familles vivant avec l'autisme. Les rencontres en personne ont cédé la place aux rencontres virtuelles, qui permettent aux prestataires des services de navigation de continuer à éduquer et à soutenir les parents dans le cadre de séances d'information en ligne sur le financement, d'ateliers et de groupes de soutien aux parents. En outre, nous continuons d'aider directement les familles qui souhaitent s'inscrire ou soumettre des demandes de financement au Programme ontarien de services en matière d'autisme (POSA).

Les occasions d'apprentissage social (OAS) représentent une grande partie de notre soutien aux enfants et aux jeunes autistes et à leurs familles, et la COVID ne nous a pas empêchés de les aider. La créativité a pris son envol dans toute la province! Des entreprises locales (Crock a Doodle, serres, boutiques d'artisanat, pizzerias, etc.) se sont jointes à nous pour offrir aux familles des trousseaux d'activités à domicile. Sur les photos que les familles nous ont fait parvenir, la joie que mes collègues et moi pouvons observer sur le visage des enfants nous donne la motivation de poursuivre le travail que nous adorons, même si c'est en mode virtuel pour l'instant.

À toutes les familles d'Autisme Ontario, ne lâchez pas! Ça va bien aller! Il me tarde de pouvoir vous rencontrer de nouveau en personne! ■

L'art de la pleine conscience

NOUS LOGEONS TOUS À LA MÊME ENSEIGNE



par Stephanie Moeser, BSW, MSW, RSW

NOUS VIVONS TOUS différemment la situation actuelle. Certains d'entre nous s'en accommodent bien et apprécient de lever le pied de l'accélérateur; certains se sentent dépassés et doivent cumuler plusieurs rôles; certains travaillent en première ligne dans le système de santé ou ont des membres de leur famille qui y travaillent; et certains peuvent avoir de la famille ou des amis directement touchés par la COVID-19. Toutes ces expériences peuvent soulever une diversité d'émotions, de pensées ou même de sensations physiques. Il n'y a pas de bonne ou de mauvaise manière de réagir. Il n'existe pas de feuille de route, et même si c'était le cas, chacun d'entre nous aurait un parcours complètement différent.

Dans ce contexte, il peut être utile de prendre conscience de chaque moment qui passe. Sans jugement, et avec compassion. Il n'y a pas de mauvaise façon de s'y prendre. Tous nos sentiments sont valables. Essentiellement, cette prise de conscience sans jugement de chaque moment est la pleine conscience.

Quand on parle de « pleine conscience », de nombreuses personnes pensent tout de suite à la méditation. La méditation comme telle et la pleine conscience sont deux choses différentes. Face au concept de méditation, les gens pensent souvent qu'il s'agit de se vider l'esprit. De ne pas s'inquiéter. De s'apaiser. De vivre une sorte d'expérience



ineffable de béatitude spirituelle. C'est peut-être le cas des moines qui pratiquent quotidiennement la méditation depuis de nombreuses années. Entendons-nous, c'est une voie noble et pleine de foi, mais qui n'est pas à la portée de la plupart des gens. Ce ne doit pas non plus être le but visé. La pleine conscience, c'est s'ouvrir aux sensations et aux sentiments du moment présent, au chaos, à la confusion, à tout ça.

Je reprendrai ici une citation souvent évoquée du Dr Kabat-Zinn, et qui est ma définition préférée :

« La pleine conscience consiste à ramener son attention sur le moment présent, d'une façon particulière et sans porter de jugement. »

Arrêtons-nous quelques minutes sur cette définition. Elle ne suggère en rien la quête d'une quelconque forme de tranquillité ou de paix intérieure. Si seulement il était si facile de cheminer par la pensée vers la paix et la tranquillité. « Redoubler d'efforts » pour atteindre la paix de l'esprit et se débarrasser des inquiétudes mène inévitablement à la frustration et à l'intensification des soucis.

La pleine conscience est l'acceptation

Je comprends qu'il est difficile d'accepter l'état actuel des choses, et nos réactions à ce sujet. Nous voulons que les choses reviennent à ce qu'elles étaient, et si elles ne peuvent pas y revenir maintenant, nous voulons savoir QUAND elles y reviendront. Quand retrouverons-nous

l'ancienne normalité? Est-ce que la nouvelle normalité ressemblera à l'ancienne normalité? Pendant combien de temps encore pourrai-je tenir? Pendant combien de temps encore mes enfants seront-ils privés d'apprentissage en classe, avec moi comme seul enseignant? Quand retrouveront-ils leurs programmes, leurs thérapies et leurs cours de natation? Quand pourront-ils à nouveau aller s'amuser au parc?

La pleine conscience relève d'une intention délibérée de laisser les sentiments être ce qu'ils sont

Ressentir les sentiments. En faire l'expérience. Ne pas s'y accrocher. Les vivre comme observateur, puis les laisser aller. Vous vivez les émotions et les sensations; vous n'êtes pas les émotions et les sensations. Banale en apparence, cette distinction est en fait déterminante. Cette distinction est importante. Accordez-vous cette pause. Permettez-vous d'accepter ce qui émerge et les sentiments que vous ressentez, même si ça semble pour l'instant difficile.

Si l'idée de vous permettre de ressentir toutes ces émotions et sensations vous dépasse, ce n'est pas grave. Dans ces moments, choisissez une activité qui peut vous distraire, une activité vers laquelle concentrer votre intention et votre attention. Ça peut être construire des Legos avec votre enfant, cuisiner, jardiner, écouter (vraiment écouter) de la musique, laver la vaisselle à la main, faire du yoga, se promener en respectant la

distanciation sociale.... Essentiellement, trouver une activité qui vous recentre, même pour quelques instants.

N'oubliez pas, il n'y a pas de mauvaise façon de s'y prendre

C'est une nouvelle expérience pour nous tous. Mais ce sur quoi je mise avant tout, c'est l'importance de faire preuve d'auto-compassion. De jeter un éclairage positif sur soi-même. ■



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 ».



Learning DOT Autism Ontario

Visitez : learning.autismontario.com/fr

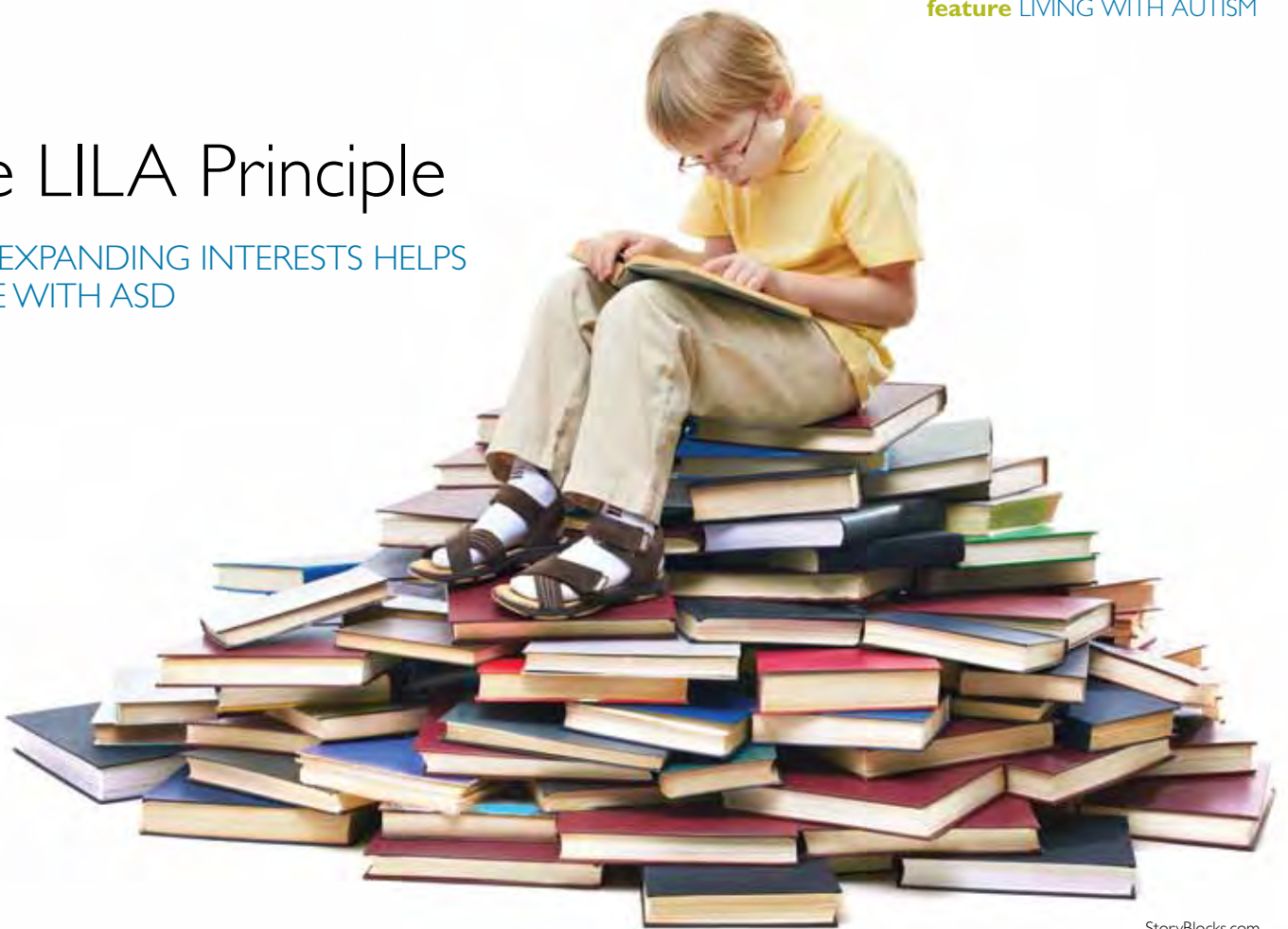
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Le nouveau portail éducatif d'Autisme Ontario regroupe à un seul endroit des ressources utiles en lien avec l'autisme. Il suffit de vous y inscrire pour avoir accès à tous les webinaires déjà présentés, à des articles éclairants et à une foule de renseignements sur le trouble du spectre de l'autisme, qui aident à suivre le cheminement d'une personne autiste, dès la réception du diagnostic et tout au long de la vie adulte.

Webinaires | Calendrier d'activités éducatives
Anciens numéros de la revue *Autism Matters*
Articles éclairants | et plus...

The LILA Principle

HOW EXPANDING INTERESTS HELPS THOSE WITH ASD



StoryBlocks.com

by Maureen Bennie, Founder, Autism Awareness Centre

OVER THE YEARS, I have tried to expand my children's interests to help them increase knowledge, keep their lives interesting, and to foster growth. This has also been an educational goal in both school and home therapy programs. My son Marc, now 22, has a great range of interests that has broadened beyond ceiling fans and *Thomas the Tank Engine*. Julia, 20, has also developed many interests such as cooking, puppetry, animation, The Muppets, cats and ballet. How did this transformation take place? How did these interests increase from just a couple to many?

I have thought about this and can say it is because of two things—something I call the LILA Principle (Leave It Lying Around) and exposure to a wide range of activities to build connections. Here is how the LILA Principle worked with regards to Marc's reading.

LILA in action: reading, music and ballet

My husband Ron and I have been avid readers for many years and buy books every month. We have always allowed both of our children access to any book on our shelves. Occasionally, I buy audio books for Ron to listen to while driving. A few years ago, I bought him Bob Barker's biography, *Priceless Memories*; Ron put it on a shelf when he was done with it. Six years ago, Marc found that audio book and began to listen to it with great interest as he knew Bob Barker's voice from *The Price is Right* game show. I decided to get him the book version as well to see what he would do. He started the CD over again and followed along with the book, running his finger along the text. He never made a mistake or got behind with turning pages, so I knew he was able to read the text. After completing the book with the CD, Marc started reading the book aloud without the CD accompaniment.

Evidence informed



Marc was most interested in celebrities. He would find different interviews on YouTube, then ask to read their book. I kept the pairing of the book and audio CD for the next three titles he wanted. By the fourth title, Marc just wanted to read aloud without having to hear the CD at all. Our avid reader was born! Marc now reads a biography every week that is 200-300 pages long. He can't read silently in his head, only aloud. He devotes two to three hours a day to reading on the weekend when school is on, daily during the holidays. He has read biographies on Bill Clinton, Betty White, Dick Van Dyck, Céline Dion, Bob Newhart, Queen Elizabeth and dozens of others. Marc was also fortunate to have a work experience placement at the local library which gave him access to all kinds of books that he began to sign out and read.

As a result of this reading, Marc now wants to visit all kinds of museums because he likes to read the plaques aloud. He now also knows that many museums will show a documentary video on topics they highlight. This has increased his interest in watching documentaries at home. When Marc reads those plaques, he gets very excited when a name comes up that he knows, such as Queen Elizabeth.

I started taking Marc to classical music concerts. He has had a lot of exposure to music his whole life as his father is a professional pianist. I took a chance last year that he might enjoy a Baroque concert featuring a solo mandolinist, Avi Avital. He liked the music so much, he asked for the CD which I purchased. Marc then began conducting to this CD and also using it for relaxation and in his yoga sessions. Avi Avital led to other concerts, one that featured a string quartet. This became a new passion and we attended the Banff International String Quartet competition this week.

I took both children to their first ballet in January. It was very modern and more like dance than classical ballet. One of the pieces that was performed

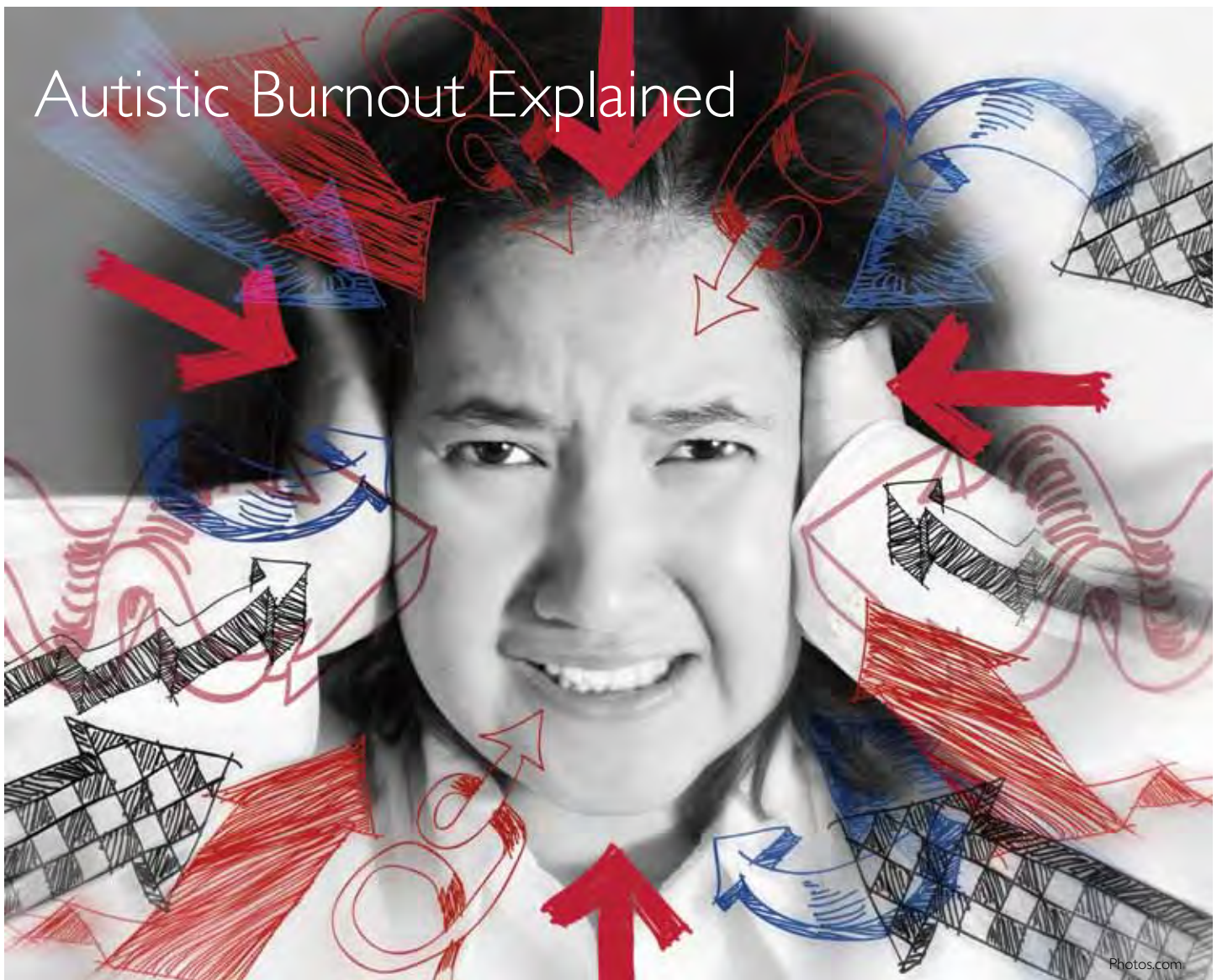
Ten tips to increase interests and expand knowledge

- 1 Leave things lying around to be discovered.
- 2 Introduce things that are related or connected to a topic of interest.
- 3 Visit places of interest. You never know what may click or grab their attention.
- 4 Volunteer. We've been volunteering at a Farmers' Market for six years. In the past two years, Marc has started eating a huge variety of fruits and vegetables from having been exposed to them in a work environment.
- 5 Read and visit your local library.
- 6 Attend all kinds of events from sports, music, lectures, plays and films—whatever you can get your hands on. Not everything will be a success or liked, but it never hurts to try.
- 7 Participate in many different activities.
- 8 Travel if you can, even if it's just an hour's drive outside of your city or town. You're bound to notice something different.
- 9 Build on an interest. For example, Julia became interested in cats after attending her first cat show. She then started following a cat foundation online. This led to the eventual adoption of our first cat (a three-year process) which then grew into a work experience job at a pet store, which is leading to a volunteer position with the cat charity once Julia turns 18.
- 10 Talk to people. Ask what they do for hobbies, ask about organizations they belong to. Be a spectator at something they participate in.

was Queen's *Bohemian Rhapsody* which began Julia's love of Queen. She discovered the Muppets did their own version of the song on YouTube so this got her researching more about the Muppets and what kinds of music they performed. Julia now wants to study puppetry when she finishes high school this year and become a puppeteer. I just ordered a documentary from the library called *Being Elmo*, which is the story of Kevin Clash, Sesame Street's Senior Puppet Coordinator. Let's see where this will lead!

Exposure to many different things will expand interests and lead to new and exciting things. Follow the LILA Principle—leaving things lying around—which allows for children to discover something in their own time and way. Every person is unique. It is our job to help create a path that leads to a meaningful, rich life.

Reprinted with permission. This article first appeared on the Autism Awareness Centre's Articles & Blogs on September 5, 2016. (<https://autismawarenesscentre.com/>) ■



by Sarah Deweerdt, Guest Writer

‘Autistic burnout’ is the intense physical, mental or emotional exhaustion, often accompanied by a loss of skills, that some adults with autism experience. Many autistic people say it results mainly from the cumulative effect of having to navigate a world that is designed for neurotypical people.

BURNOUT MAY ESPECIALLY AFFECT autistic adults who have strong cognitive and language abilities and are working or going to school with neurotypical people.

Here we describe the emerging picture of this phenomenon, how autistic adults might be able to recover from burnout and how to prevent it from occurring.

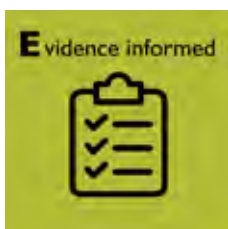
What is the experience of autistic burnout like?

Like many aspects of autism, burnout varies greatly from person to person. Some autistic people experience it as an overwhelming sense of **physical exhaustion**. They may have more difficulty managing their emotions than usual and be prone to outbursts of sadness or anger. Burnout may manifest as intense **anxiety** or contribute to **depression** or **suicidal behavior**. It may involve an increase in autism traits such as **repetitive behaviors**, increased sensitivity to sensory input or difficulty with change.

Burnout can sometimes result in a loss of skills: An autistic woman who usually has strong verbal abilities may, for example, suddenly find herself unable to talk.

How did the concept of burnout arise?

Few studies have formally investigated autistic burnout. Autism researchers have only



become aware of burnout as a phenomenon over the past five years or so. They have learned about it directly through discussions with autistic participants in person or online.

The concept reflects the growing self-advocacy movement in the autism community, which has led to an increasing focus among researchers on adults with autism and their inner experiences. But it's not entirely new: Some researchers point out that children with autism can have meltdowns or lose skills when overwhelmed by the demands of a difficult environment.

What causes burnout?

Burnout is often a **consequence of camouflaging**, or masking, a strategy in which autistic people mimic neurotypical behavior by using scripts for small talk, forcing themselves to make eye contact or suppressing repetitive behaviors. These strategies can help autistic people in their jobs and relationships but require immense effort.

It can also result from sensory overstimulation, such as a noisy bus commute; executive function demands such as having to juggle too many tasks at once; or stress associated with change.

How do autistic people recover from burnout?

That depends on the person and on what burnout is like for them. A first step is for autistic people to **remove themselves** from the situation that triggered the burnout. This could be as simple as going back to a hotel room to rest alone after a day of unpredictable social interactions at a conference. Others may need longer to recover. Some autistic people have described burnout that is so severe its effects have persisted for years. Burnout may occur more frequently and be more difficult to recover from as people get older.

Is it possible to prevent burnout?

A key strategy for preventing burnout is self-knowledge. Autistic people can learn over time which situations are most likely to trigger burnout for them. They can also watch for signs that they are getting close to burnout: Some autistic people describe feeling disconnected from their bodies or experiencing tunnel vision in this state.

Armed with this awareness, they can develop strategies to avoid burnout, such as leaving a social event early or planning a recovery day after a trip before returning to work. They can also ask for accommodations that make it easier for them to avoid burnout, such as preboarding an airplane or working from home part of the time.

Originally published in Spectrum, Autism Research News, March 30, 2020 <https://www.spectrumnews.org/> ■



Racism in ~~America~~ Canada

ACKNOWLEDGE. REFLECT. ACT.

by Jessica Bethel, Director OAP Provider List, Autism Ontario

“For those who have seen the Earth from space... the experience most certainly changes your perspective. The things that we share in our world are far more valuable than those which divide us.”

~ Donald Williams



WHAT A TIME WE ARE LIVING IN! As we navigate the new reality of life in the midst of a pandemic, some have likened the horrific mistreatment of black men and women in the United States to a pandemic. The description is apt. By definition, a pandemic is defined as “an epidemic occurring worldwide, or over a very wide area, crossing international boundaries and usually affecting a large number of people” (World Health Organization, 2020).

In the autism community, many of us have been impacted by discrimination or differential treatment of family members, friends, loved ones, clients and/or ourselves. This community understands what it feels like to be treated differently, simply because of being different from others, in ways we cannot control. Perhaps this community can understand why this is a problem and what steps we can all make to bring about real, long-lasting change.

When the events south of the border began, the initial reaction of many Canadians was that racism was not as much of

an issue here. A different story has since emerged as People of Colour (POC) have come forward to tell their stories. Systemic racism is so deeply ingrained in our society that many POC have silently accepted and endured the injustices brought upon them.

The outpouring of support from non POC has been a wonderful expression of solidarity in a time that has been so difficult due to the new realities of life in the midst of COVID-19. Yet, there is still so much more that needs to be done. Now that the momentum has started, we can keep the ball rolling by intentionally engaging in the following three steps:

1. Acknowledge that certain groups of people have experienced systemic racism

“Having a limited understanding of other cultures can lead to cultural tunnel vision, a perception of reality based on a very limited set of cultural experiences” (What Does it Mean to be Culturally Competent, www.rapworkers.com).

2. Reflect on your own biases and views

“Take your pulse” and ask yourself the following questions:

- Am I aware of my own biases?
- Where do I stand on these issues?
- Parents, you can take it one step further and ask, “are these biases embedded in the way I raise my children or interact with others?”
- Professionals can ask, “do these biases impact the ways that I interact with clients, the assessments that I use or the quality of services provided?”

3. What action needs to be taken?

Human rights activist Desmond Tutu once said, “If you are neutral in times of injustice, you have chosen the side of the oppressor.” Once you have increased your understanding of the problem and acknowledged, identified and reflected on the areas where growth is needed, you are able to act. Educate yourself and your children, employees, managers, colleagues, friends and peers and make a concrete plan to break down the barriers of systemic racism. ■

Suggested Resources

For Children:

- *Whose Toes Are Those?* Jabari Asim
- *Let’s Talk About Race*, Julius Lester
- **Kids Books That Talk About Racism**, *Today’s Parent*
<https://www.todayparent.com/family/books-kids-books-that-talk-about-racism/>
- **Your Kids Aren’t Too Young to Talk About Race: Resource Roundup**
<https://www.prettygooddesign.org/blog/Blog%20Post%20Title%20One-5new4>

For Adults/Professionals:

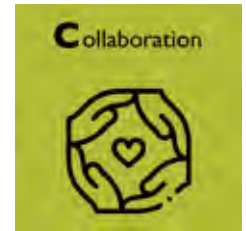
- **Cultural Competence Resources**
<http://rapworkers.com/resources/cultural-competence/>
- **Harvard Implicit Association Test (IAT)**
<https://implicit.harvard.edu/implicit/takeatest.html>
- **A Guide to Discussing Identity, Power and Privilege- University of Southern California School of Social Work**
<https://msw.usc.edu/mswusc-blog/diversity-workshop-guide-to-discussing-identity-power-and-privilege/#closing>
- bit.ly/ANTIRACISMRESOURCES



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



OUR CHAPTERS have been very busy this spring, bringing take-home kits and virtual activities to families across the province! A special thank-you goes to all of our volunteers, who've been busy engaging with our community, planning new activities, and continuing to support families.

Autism Ontario's **London Chapter** is excited to partner with Digital Extremes for the upcoming 2020 TennoCon online gaming conference, to be held on Saturday, August 1. A portion of the proceeds from the event will go to the chapter. We are grateful for partnerships with Digital Extremes and other community-focused organizations.

On May 15, our **York Region Chapter** hosted its first Virtual Dance Party with Hand Over Hand, Autism Teenage Partnership, and Viability Employment Services. This

▼ Ashlee Dagenais and her Sensory Kit



▲ London TennoCon

fun evening had a costume contest, music from DJ Ben, and a comedy room with Michael. We can't wait to do it again!

Our **Niagara Region Chapter** has been busy putting together all sorts of take-home kits for families to enjoy. Ashlee got a Sensory Kit and let us know, "These sensory toys have really helped me during these different times. I'm ever so thankful to everyone involved."

On May 21, our **Windsor-Essex Chapter** had the incredible pleasure of hosting a live Zoom Q&A with Temple Grandin. It was wonderful to hear Temple speak and answer questions from our families in the community. The chapter is also continuing to host online music classes with Candice Twees from Inspired Sounds Music Therapy. Everyone enjoys singing and dancing to the different songs each Wednesday evening! The Windsor-Essex Chapter is grateful for the understanding and support from our families and our community and can't wait to come up with more ideas of fun activities and online events for families in the Windsor-Essex community.

The very popular "Kids Club" run by our **Simcoe County Chapter** has also gone digital. The weekly event with Jill from Wild

Life Fitness, held on Zoom, has the chapter's families dancing, moving, grooving, and crafting. The chapter has also partnered with wonderful local businesses like Rising Phoenix Yoga and Fitness to offer weekly virtual yoga sessions for our Simcoe County families. Yoga is beneficial to children in many ways and can help them to manage stress through breathing, awareness, meditation and healthy movement. The Simcoe County Chapter would like to extend its gratitude both to its participating families for their flexibility and its amazing partners, who've helped us navigate these unusual times.

Also in Simcoe County, Muskoka and Parry Sound region partnered with HANDS, The Family Help Network serving the North

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.

and Northeastern area. Melissa Hancocks, an ASD Family Support Worker, ran the session, which involved painting pictures with string. We received some stunning results!

Our **Durham Region Chapter** has been creative with a number of fun family activities and take-home kits, including painting parties, cookie decorating, balloon animal tutorials and fun experiments.

That's it for now! Looking for a way to get involved? We're always looking for new volunteers. Contact your local Autism Ontario chapter for exciting opportunities in your region. ■



◀ Jake Hannon and his nana, Loma Keal ▲ ...and a sample of the art



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: _____

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



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

A self-addressed envelope is enclosed for your convenience.
Incorporated as Autism Ontario
Charitable Registration #11924 8789R R0001



OAP Provider List

THE PROVIDER LIST is hosted by Autism Ontario and is available at: www.oaproviderlist.ca.

It is an online listing of clinical supervisors of behavioural services for children and youth with autism. 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.

The provider list is currently voluntary, meaning that families receiving Childhood Budgets can continue to hire clinical supervisors who have not yet joined the list as long as they are working towards the qualifications and submit a signed attestation form.

HAS YOUR ADDRESS CHANGED?

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

PUBLICATIONS MAIL AGREEMENT # 40910519

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RETURN UNDELIVERABLE CANADIAN ADDRESSES TO:

AutismONTARIO

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

LA LISTE DES FOURNISSEURS est hébergée par Autisme Ontario et disponible sur le site oaproviderlist.ca/fr.

Il s'agit d'une liste en ligne de superviseurs cliniques chevronnés et formés en matière de services comportementaux pour les enfants et les jeunes atteints d'autisme. 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 confirment les qualifications de ces derniers.

L'utilisation de la liste des fournisseurs est actuellement facultative, ce qui signifie que les familles qui reçoivent un budget pour les services aux enfants peuvent continuer à engager des superviseurs cliniques qui ne se sont pas encore inscrits sur la liste, tant qu'ils sont en voie d'obtenir les qualifications voulues et qu'ils présentent un formulaire d'attestation signé.