Autism MATTERS

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PERSPECTIVES

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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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What's **Inside** WINTER 2020

features

info autisme

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News and Noteworthy

Strange Times

THE TIMING OF THIS ISSUE of *Autism Matters* coincides with what feels, to many, like seismic shifts of uncertainty about all that is happening here in Ontario, nationally and internationally. Moment to moment reports bombard our screens about COVID-19, unrest across Canada on who decides about land, acknowledgment of historical wrongs nationally and internationally and growing gaps between those who have and those who do not.

Closer to home, we wonder what responses there will be to a proposed blueprint for a National Autism Strategy or a housing strategy that supports people with neuro-developmental disabilities to and through adulthood. And what about the Ontario Autism Program? Will the Implementation Team find ways to realize the recommendations from the OAP Advisory Panel's Report largely endorsed by Ontario Minister Todd Smith and more broadly by a very diverse autism community in Ontario? I hope you've seen our website-posted submission to the Ontario Minister of Finance as part of his pre-budget consultations (www.autismontario.com).

All of these matters prompt varying degrees of shorter and longer term anxiety. How does one begin to cope with all these circumstances or find ways to counteract the power of misinformation?

I propose that we stop and consider what we can do in this very moment to think about what these matters do or don't mean for you personally or for your family, make choices that alleviate anxiety rather than adding to it, and connect with people who can join you in helpful conversations or activities that impact the moment or the day you are in right now.

I encourage you to take a moment to read many of the excellent perspectives and information in this issue of ***Autism Matters***. The topics proactively address many of the points noted above including the importance of family, a mother's perspective, information on Jordan's Principle and indigenous people on the spectrum, steps for transitioning into adulthood, what generalization means, the benefits of volunteerism, and thinking about mental health and autism. It will be time well spent.

Marg Spoelstra, Executive Director

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.

Strategic Directions

Look for these icons to identify articles in this issue with aspects of Autism Ontario's strategic priorities:

1. *Effective marketing and fundraising*
2. *Building a unified organization*
3. *Opening doors for adults*
4. *Educating educators and professionals*
5. *Using information technology to collaborate, learn and share*
6. *Expanding our reach*

47th Annual General Meeting (AGM)

Autism Ontario will hold its 47th Annual General Meeting on Saturday, June 6, 2020 at the Holiday Inn Toronto-Yorkdale, 3450 Dufferin Street, Toronto.

The call for nominations for openings on the Board of Directors will be broadly distributed during the week of March 23. The notice will describe the skills and experience that the Nominations Committee seeks and will ask for suitable interested candidates to contact the Committee. Individuals with an up-to-date membership will have opportunity to submit nominations electronically or by regular mail. Deadline for all nominations to be received by the Committee is 5:00 p.m. on Friday, April 9, 2020.

In keeping with our commitment at the 2019 AGM to reduce our environmental impact, as well as our mailing costs, we will distribute all AGM details and information on voting procedures via email notification. If you have not already done so, please let us know if you prefer to receive a paper ballot. To advise us of an email change or for questions on membership, contact giftandmembership@autismontario.com or call 416-246-9592 ext. 247.

Jordan’s Principle

WHY IT MATTERS FOR FIRST NATIONS CHILDREN WITH ASD AND THEIR FAMILIES

by Michael Cnudde

Unsplash.com/NandhuKumar

JORDAN RIVER ANDERSON, from Norway House Cree Nation in northern Manitoba, was born with complex medical needs. Due to his diagnosis, he spent most of his life in a Winnipeg hospital. Once he was cleared to return home to receive home care, it became unclear who was responsible for providing it: the federal government due to his Indigenous Status, or the provincial government, which was mandated by the BNA Act to provide health care for all citizens. The federal and provincial government could not come to an agreement over who was responsible for his in-home medical expenses, and Jordan never had the chance to return home. He died in hospital at age five.

After Jordan River Anderson's death, First Nations peoples determined that no child should ever be deprived of the healthcare standards other Canadian children enjoy. After a series of human rights challenges by First Nations in 2017, the Federal Government announced it would fully implement Jordan's Principle.

Jordan's Principle is a child-first and needs-based principle that applies to all First Nations children, whether they live on reserve or off. Briefly stated, it ensures "substantive equality" in that no First Nations child should experience delays in receiving the same public services that are available to other children.

Ken Robertson, a member of the Bear Clan of the Secwepemc People of British Columbia, notes that in Jordan's Principle, he sees parallels with the Ontario Autism Program. "I'm seeing, as a parent of three children with Autism Spectrum Disorder (ASD), parallels with the Ontario system when it comes to a more proactive approach to dealing with the disorder," says Robertson, who is also a Member of Autism Ontario's Board of Directors and its Treasurer.

Stemming from his experience in raising children on the spectrum, Robertson was also responsible for the creation of Four Directions Autism, a parents' support group for off-reserve First Nations, Inuit, Métis, and Non-Status parents who have children on the autism spectrum. "We have to do a better job of helping each other. It's a long way to come from," said Robertson. "We, for sure, have a lot of what it takes to do a better job."

Because of the dedication to "substantive equity," Jordan's Principle opens the door for First Nations families of autistic children to receive the interventions they have been waiting for and have had difficulty accessing.

Robertson calls Jordan's Principle a "request-based" system that a parent or caregiver must navigate. This is often done with the help of a Service Coordinator, depending on the province or territory the child resides in. "A parent has to understand they need to have a case… A lot of people work with the family," said Robertson. "It's always difficult that as a parent, you must get a letter from your teacher, doctor and your chief and council when gathering a support letter for your child."

Jordan's Principle covers a wide range of public health services, such as mental health, medical, special education, dental care, physical therapy, medical equipment, physiotherapy and more, which are culturally-based, and funded on a case-by-case basis. It provides payment from the government that first received the request for medical care, thereby cutting out delays. All First Nations children, aged 0-18 (or 19, depending on the jurisdiction) are eligible. Applications must be submitted by parents or guardians of a First Nations child, or their authorized representative, and First Nations youth aged 16 and older may apply for themselves.

"Many children are receiving services now where they were not receiving anything," said Robertson. "What it stands for and what it is, we've made big strides. We all have a role in creating First Nations services for children. I am happy [Jordan's Principle] is here." ■

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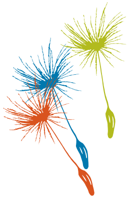

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Generalization

APPLIED BEHAVIOUR ANALYSIS (ABA): THE SCIENCE OF BEHAVIOUR DEFINED BY SEVEN CHARACTERISTICS OR DIMENSIONS

by Shabina Bari, MSCPsych, Senior therapist, AlphaBee ABA Services

A BEHAVIOUR CHANGE PROGRAM must include all of these seven defining characteristics in order to be considered ABA: Applied, Behavioural, Analytic, Technological, Conceptually Systematic, Effective and Generality. This article looks specifically at the last dimension—Generality.

A behaviour change program is said to have generality when it produces behaviour change that occurs in other environments, is maintained over time, and extends to other behaviours. The generalization of a behaviour change program is very important when a child receives ABA therapy at a centre or at home. When a skill is learned or a behaviour is reduced, it is crucial that this skill or behaviour reduction continues at home and not just with the person who has taught the new skill or implemented the behaviour reduction program. A program that promotes generalization, plans for how skills will be transferred to a different person and different environments.

When addressing generalization, it is important to note that there are two types: response generalization and stimulus generalization. Response generalization occurs when a child engages in a behaviour that serves the same purpose as a trained target behaviour, the behaviour that is being developed. For example, John is taught to fold his socks by placing them together and *rolling* them up in a ball. When doing laundry, John figures out that he can also fold his socks by putting them together and *folding* over the top. This is easier for John and he is able to fold more socks per load.

Stimulus generalization is when an antecedent (something that occurs before a behaviour) is evoked, has been reinforced and therefore, the behaviour occurs in similar circumstances. For example, when a child learns to respond correctly to "touch dog" when pictures of a dog, cup and book are on the table and then at a later date with his mom at the park he can correctly point to a dog when asked, "Where is the dog?" stimulus generalization has been demonstrated.

Skills can also be generalized across time, place and person. When learning a new skill or decreasing a challenging behaviour, ideally a child should be able to do this task with anyone, anywhere and even one week later. However, for many children with ASD, generalization of skills needs to be taught.

Let's look at a few scenarios and examples of why generalization is essential and the potential repercussions of not planning for generalization. We will also look at how a therapist can teach for generalization.

Scenario 1

Brandon learned at his therapy centre to identify a car by saying "car" when shown a specific picture of a red car that his therapist has in her materials bin.

Here's what would happen if generalization was not taught.

When reading a book with his therapist, there was a blue car on the page. The therapist, knowing that he was able to identify a car, points to the car and says, "Brandon, what's that?" Brandon does not respond. The reason for this is that Brandon has only learned to call the specific red car his therapist showed him a "car." To ensure that this does not happen in the future, Brandon's therapist can use what is called multiple exemplars, showing him different pictures of various colours and models of cars so he knows that the word "car" is used for all cars.

When learning a new skill or decreasing a challenging behaviour, ideally a child should be able to do this task with anyone, anywhere and even one week later.

Scenario 2

Alice is able to build a structure with blocks, following the model built by the therapist. The therapist used a variety of blocks and structures to ensure that Alice can make a structure with any type of blocks. Alice loves doing this activity with her therapist. Upon arriving early to the centre one day, a new staff member worked with Alice. Knowing that block building was her favourite activity, the new therapist began building a structure for Alice to copy. Alice was not able to copy the new therapist's structure.

The reason for this was that Alice had only learned this activity with her usual instructor. To promote generalization to different people, once the skill was learned, Alice should do this activity with a novel person such as a different therapist or a parent.

Scenario 3

Alex learned to wash the dishes at his therapy centre. He learned this skill with his primary therapist as well as with novel therapists and his mother, who has been coming to the centre for regular parent training. His mother was very happy that he could do the dishes and was looking forward to Alex helping his siblings with household chores. However, after dinner one night, Alex's mom asked him to do the dishes. He did not respond and when taken to the kitchen, was not able to complete the task.

New environments are also a crucial step in generalization of skills. Alex knew the instruction at the centre but was not able to complete this step in a new environment, such as at his home. To plan for this, his therapist can teach him to wash dishes in various places and sinks such as the kitchen of his home and school.

Let us finally take a look at a successfully generalized skill.

Max has learned to cut out shapes on paper. When teaching the skill, the therapist used a variety of shapes and different types of paper such as construction paper, card stock and printer paper. The therapist also used scissors she picked from the arts and crafts bin, ensuring that they were different every time she taught him. The therapist had Max cut shapes at his therapy table as well as at the craft table during craft time, which was led by

AlphaBee provides Applied Behaviour Analysis (ABA) based programs to children and youth with autism. You can find **AlphaBee** along with other service providers and professionals on the OAP Provider List, which is an online listing of Clinical Supervisors of behavioural services for children and youth with autism. It is a resource Ontario families can use to search for, select, and confirm the qualifications of their autism behavioural service providers. https://www.autismontario.com/programs-services/finding-providers-and-professionals.

another person. By teaching him to cut shapes under all these conditions, Max has learned to cut many shapes on different types of paper using any scissors. He has learned to cut out shapes anywhere and when given the instruction by anyone. For Max, cutting shapes is therefore a successfully generalized skill.

Putting it all together

For a skill to be successfully taught, it must be generalized across places, people and stimuli. An individual must be able to complete a skill with a variety of people (such as parents and different teachers). The individual must be able to complete the skill anywhere (not only where it was initially learned) and they must be able to complete the skill with multiple items that are similar. ■

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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**.

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INFO Autisme

Ces jours où j'ai l'impression de ne pas en faire assez

StoryBlocks.com

par Maria Garito

AUJOURD'HUI EST UNE DE CES JOURNÉES!

Une de ces journées où ma tête prend le dessus et me dit que je n'en fais tout simplement pas assez. Que mon fils ne va pas bien, parce que je n'ai pas répondu à ses besoins.

Alors que c'est déjà assez difficile d'être parent dans ce monde au rythme effréné où il faut jongler avec l'impossible, mais élever un enfant autiste implique toute une série d'attentes que je suis loin de maîtriser.

Aujourd'hui, je me demande si je prends la bonne décision de l'envoyer à l'école.

- Est-ce que j'en fais assez pour faire valoir ses droits?
- Est-ce que je le force trop à s'intégrer à un système qui n'est pas fait pour lui?
- Est-ce que je perturbe ses routines en le retirant de l'école pour une thérapie?
- Est-ce que la thérapie est utile?
- Est-ce qu'il est fatigué?
- Est-ce qu'il a besoin de se reposer un peu de tout ça?

Et quand votre enfant est non verbal, chacune des décisions que vous prenez en son nom se transforme en jeu d'essais et d'erreurs. Je ne peux pas lui demander ce qu'il pense, parce qu'il ne peut pas me le faire savoir, sauf pour les quelques demandes qu'il fait au sujet de la nourriture et de certaines activités.

J'aimerais ardemment qu'un jour il me dise ce qu'il a fait à l'école, ou ce qu'il ressent. Je ferais n'importe quoi pour brancher mon cerveau au sien, afin qu'il puisse me faire voir comment il perçoit le monde.

Je le vois essayer. Essayer de communiquer avec moi. Et j'interprète. J'interprète son humeur, sa réticence à monter dans la voiture, son sourire quand je lui mets ses bottes. Je vois à quel point il est heureux quand il entre dans son centre de thérapie en me saluant de la main. Je vois avec quelle facilité il entre dans la cour de récréation de l'école et se précipite vers la structure de jeu, tout en tournant la tête pour me voir lui sourire. Je vois à quel point, quand nous nous préparons à faire une balade en voiture, il est enchanté et saute de joie en battant des mains.

Ensuite, je me calme. Je me rappelle que même si dans ma tête je n'en fais pas assez, pour mon fils je suis tout.

Et même s'il ne peut pas me dire qu'il va bien, il me fait savoir qu'il m'aime par son sourire, ses câlins et ses bisous.

Et peut-être que pour aujourd'hui, c'est assez.

(Publié à l'origine sur www.themighty.com) ■

Autisme x 2 : la transition vers l'âge adulte

L'AVENIR S'ANNONCE PROMETTEUR

par Maureen Bennie

IL Y A QUELQUES ANNÉES, j'ai affiché une publication à propos de mon expérience concernant l'éducation de mes deux enfants ayant un trouble du spectre de l'autisme. J'ai écrit ce texte en me remémorant la petite-enfance de mon fils et ma fille. Récemment, une personne vivant en Chine m'a contacté pour me demander si elle pouvait traduire la publication, car celle-ci permettrait d'encourager les familles et de leur donner de l'espoir quant à l'avenir.

Mes enfants ont terminé l'école depuis près de deux ans et ont bien entamé leur vie d'adulte. Marc est sur le point d'avoir 22 ans et Julia aura 20 ans le mois prochain. J'aimerais vous partager où nous sommes rendus, car il est difficile d'imaginer ce dont aura l'air l'avenir de nos enfants lorsqu'ils sont jeunes : nous avons l'impression que les choses ne changeront jamais et ne s'amélioreront pas et nous n'arriverons pas à voir le résultat de tous nos efforts.

La transition vers l'âge adulte

Lorsque je mettais en place un plan de transition pour Marc et Julia, je me suis concentrée sur quatre sphères pour éviter d'être submergée par la situation ou de devenir distraite. Voici ces quatre sphères :

1. La poursuite des études
2. Les occasions d'emploi
3. Les activités de loisirs et récréatives
4. Les temps libres

Je gardais en tête que ces quatre sphères pourraient les aider à acquérir des compétences leur permettant d'avoir un mode de vie autonome et d'éprouver un sentiment de bien-être, le tout en décuplant leur épanouissement.

La poursuite des études

Pour encourager la poursuite de leurs études, j'ai examiné les cours de formation continue, les cours offerts par les bibliothèques publiques (dont beaucoup sont gratuits) et ceux d'une petite université qui sont donnés aux personnes ayant un trouble de développement. Je me suis aussi penchée sur les cours proposés au sein de la communauté ainsi que les conférences données dans la ville. J'ai réussi à rassembler d'excellentes options permettant à Marc et Julia d'approfondir leurs champs d'intérêts.

Voici quelques exemples :

- Les cours d'informatique
- Les cours de premiers soins

- Les cours sur la santé et la condition physique
- Le tutorat en mathématique ou en lecture
- Les cours de musique et d'art

Mon fils a toujours apprécié être dans en milieu scolaire, il désirait donc poursuivre ses apprentissages dans un tel contexte. Julia était plus hésitante, mais au bout du compte, après que je lui ai démontré à quel point l'université était différente de l'école, elle était prête à essayer. Elle n'aurait pas à rester sur place toute la journée et des restaurants se trouvaient partout sur le campus. Elle était intriguée et s'en était assez pour la motiver à essayer de suivre un cours par session.

Les occasions d'emploi

En ce qui a trait au travail, j'ai commencé très tôt et j'ai fait faire du bénévolat aux enfants dans un marché de producteurs local à raison d'une fois par semaine lorsqu'ils avaient 11 et 13 ans. Les quarts de travail étaient de 3 heures et l'environnement était agréable; le travail se faisait à l'extérieur, sans musique forte ni d'espaces clos. Cette expérience fût un grand succès et leur a permis de tirer des leçons : ils ont appris à relever d'un gestionnaire, à porter un uniforme, à se voir interdire leurs appareils technologiques et à avoir chacun une description de poste et des tâches à réaliser. Leur indépendance s'est accrue au point où ils n'ont maintenant besoin que de très peu de supervision dans ce travail. En prime, mon fils a maintenant ce régime alimentaire axé sur les fruits et les légumes qui provient, je crois, de l'exposition constante à ces aliments au sein d'un environnement paisible. Il faut savoir que jusqu'à l'âge de 16 ans, Marc avait l'habitude de manger moins de 15 aliments.

Julia rêvait de travailler avec les chats. Nous nous sommes donc impliqués auprès de la fondation Meow (Meow Foundation) lorsqu'elle avait 14 ans même s'il faut avoir 18 ans pour faire du bénévolat à cet endroit. Pendant 4 années, je me suis assurée que Julia se familiarise avec tous les aspects de l'organisme en participant, par exemple, aux journées d'adoption, aux collectes de fonds, aux visites à l'animalerie et au parrainage des chats de l'organisme lors de chaque Noël. Nous avons aussi adopté un chat. Lorsque Julia a eu 18 ans, elle a fait, avec mon soutien, une super entrevue pour le coordonnateur des bénévoles. Je crois que l'habileté de Julia à reproduire toutes les expressions faciales des chats ayant figuré, au fil des ans, sur le site Web de l'organisme est ce qui l'a le plus impressionnée.

Nous avons participé à plusieurs séances de Prêts, disponibles et capables puisque Marc aime les situations d'apprentissage formel. Il affectionne les films et a obtenu une expérience de travail de 5 mois dans un cinéma à proximité de la maison. Il excellait dans ce travail et il attend actuellement de savoir s'il obtiendra un emploi permanent et rémunéré à cet endroit.

Mes deux enfants font du bénévolat à raison de deux fois par semaine dans une association pour les personnes ayant un trouble du spectre de l'autisme qui possède une banque alimentaire desservant uniquement les personnes ayant un TSA et leurs familles. Julia et Marc créent la liste d'épicerie, réalisent la saisie de données, font l'épicerie chaque semaine et placent les articles dans la bonne catégorie. Ils acquièrent beaucoup de compétences nécessaires à la vie quotidienne dans un environnement authentique!

Les activités de loisirs et récréatives

Mon travail avec l'approche à faible stimulation (Low Arousal Approach) m'a appris que la pratique régulière d'activités physiques est importante pour contenir l'anxiété. Nos enfants font de la natation, jouent aux quilles et s'entraînent 3 fois par semaine.

Marc aime les cours organisés qui se font en groupe alors il suit des cours de danse, de yoga, d'équitation et il a récemment commencé l'aquaforme. L'expérience s'est avérée merveilleuse pour lui parce qu'elle combine son amour pour l'eau à celui pour la musique.

Julia, elle, suit des cours de peinture à raison d'une fois par semaine au sein d'un groupe communautaire. Elle se débrouille très bien et a récemment participé à une exposition d'un mois qui lui a permis d'amasser un peu d'argent qu'elle consacrera à un voyage qu'elle veut prendre. Elle ne voulait pas participer à l'exposition d'art, mais une fois sa source de motivation trouvée, elle s'est lancée.

Chaque semaine, Julia suit aussi un cours culinaire et a un programme de cuisine à la maison qu'elle réalise à deux reprises. Depuis que j'ai ajouté des tâches à la liste des courses qu'elle fait deux fois par semaine, elle doit maintenant acheter de la nourriture, aller chercher des livres à la bibliothèque et retourner les bouteilles au dépôt de recyclage. Elle conserve l'argent, mais doit s'en servir une fois par mois pour acheter du matériel qui se trouve sur la liste des dons nécessaires pour les chats de la fondation Meow.

Les temps libres

Lorsqu'il est question des temps libres, les enfants ont des intérêts qui sont communs et d'autres qui diffèrent. Ils jouent ensemble à la Wii pendant les fins de semaine et aiment tous deux faire des recherches sur YouTube concernant des sujets qu'ils apprécient. Marc est un avide lecteur qui lit à haute voix près de 3 heures par jour. Ses livres de prédilection sont les ouvrages documentaires pour adultes. Il se plaît aussi à méditer sur de la musique classique dans sa chambre une fois par semaine pour une période d'une heure. Les fins de semaine, les enfants vont voir des films, des pièces de théâtre, des spectacles de danse et des concerts, et assistent à des conférences à la bibliothèque.

On pourrait croire que toutes ces activités coûtent une fortune, mais ce n'est pas le cas. Je me suis inscrite à un programme qui s'appelle la carte d'admission équitable (Fair Entry card). Cette carte permet une réduction considérable du prix d'entrée dans toutes les installations de loisirs de la ville. Puis, j'ai découvert qu'en allant à la billetterie de l'orchestre symphonique une heure avant que la programmation ne commence, il est possible d'obtenir des billets pour seulement 25 $ plutôt que 90 $. Nous avons aussi une carte Accès 2 qui permet d'obtenir deux entrées pour le prix d'une lors de nombreux évènements à travers la ville et dans tout le Canada.

Je vous invite à contacter l'association pour l'autisme ou le centre de ressources pour les personnes handicapées de votre région. Ils pourront vous partager l'information quant à la façon d'accéder gratuitement ou à moindre coût à diverses activités. Les bibliothèques municipales offrent elles aussi beaucoup de possibilités et représentent d'importants carrefours communautaires pour toutes sortes d'activités.

En conclusion

Bien que notre entrée dans le monde des services pour adultes fût difficile et effrayante, les choses vont bon train maintenant que la période initiale d'ajustement à cette nouvelle vie en dehors de l'école est terminée. Je pressens la poursuite de grands progrès et d'apprentissages chez Marc et Julia puisqu'ils sont tous deux heureux et en santé. Ils sont toujours de meilleurs amis, mais prennent leur envol et font les choses qu'ils aiment chacun de leur côté tout en se rassemblant pour les activités qu'ils aiment faire ensemble, comme la natation. Je n'aurais jamais pensé, lorsqu'ils étaient petits, que leurs vies seraient aussi bien qu'elles le sont en ce moment. Tout ce travail et cette planification acharnés ont finalement porté fruit.

Continuez vos efforts, car bien qu'il soit difficile d'imaginer l'avenir de nos enfants lorsqu'ils sont petits, leur donner des bases solides dans une variété de domaines est ce qui les aidera à l'âge adulte.

Cet article, paru sur la page Articles & Blogs du Autism Awareness Centre le 4 février 2019, a été reproduit et traduit avec l'autorisation de l'organisme. (https://autismawarenesscentre.com/)

La traduction de cette ressource a été effectuée par Ann-Alexandre Gauthier, de l'Université Laval, sous la direction d'Alexandra Hillinger. Autisme Ontario souhaite les remercier pour leur généreux travail, qui rend ces informations importantes accessibles aux francophones de l'Ontario.

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.

Chaque année, le numéro d'automne de la revue *Autism Matters* (qui comprend une section en français – *Info Autisme*) se veut notre document éducatif annuel. Depuis déjà 14 ans, Autisme Ontario fait parvenir gratuitement cette édition automnale d'*Autism Matters* à toutes les écoles de l'Ontario. Cette année, les écoles recevront notre revue gratuite pour la dernière fois.

Nous tenons à rappeler que les quatre numéros trimestriels d'*Autism Matters* contiennent 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. 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.

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Présentation d'un exposé de M. Mackenzie Salt, Ph.D., à la 38e assemblée annuelle de l'Association de linguistique des provinces atlantiques, 2014. Photo crédit : Anthony Lister

Mackenzie Salt, Ph.D.

PROGRAMME POUR AIDER LES ADULTES AUTISTES, LES FAMILLES ET LES FOURNISSEURS DE SOINS.

par Michael Cnudde

Au début de sa carrière académique en tant que chercheur, le M. Mackenzie Salt, Ph. D. a constaté des problèmes dans des premières études consacrées à l'autisme. Ces études, dit-il, présentaient un problème de reproductibilité—un aspect essentiel de tout processus d'examen par les pairs—et celles qu'on parvenait à reproduire étaient quand même boiteuses.

« **LORS DES ÉTUDES ANTÉRIEURES** impliquant les enfants, on a jumelé un enfant avec un adulte, qui faisait figure d'autorité aux yeux de l'enfant, » déclare Salt. « Cette situation créait un déséquilibre des pouvoirs, puisque l'enfant pouvait s'efforcer simplement de plaire à l'adulte. »

Il trouvait préoccupant le fait que ces études impliquaient toujours des enfants ayant un trouble du spectre de l'autisme (TSA), et jamais des adultes.

M. Salt, qui a obtenu son doctorat du programme de sciences cognitives du langage au Département de linguistique et de langues de l'Université McMaster, trouvait que quelque chose manquait. Dans sa thèse de doctorat intitulée *Deficits or Differences? A New Methodology for Studying Pragmatic Language in Autism Spectrum Disorder*, il a créé une nouvelle méthodologie basée sur l'observation des individus autistes en interaction avec les gens en contexte naturel dans le but de tirer des conclusions sur la manière dont les personnes autistes interagissent dans la vie de tous les jours. Son étude fut la première portant sur les communications entre les adultes sur le spectre. En tant que personne TSA, Salt trouvait sa recherche particulièrement importante. « Je souhaitais aider les gens par ma recherche, » dit Salt. « Je souhaitais aider les gens maintenant et constater que mes efforts avaient un impact direct sur ma communauté. »

Salt, qui travaille présentement à titre d'entrepreneur et de chercheur indépendant au sein de l'équipe de recherche sur l'autisme de l'Université McMaster (MacART) en plus d'agir à titre d'évaluateur de programme pour Autisme Ontario, collabore avec l'Agence de la santé publique du Canada (ASPC) à l'élaboration de programmes qui viennent en aide aux adultes, aux adolescents, à leurs familles et aux fournisseurs de soins : Les programmes *Mood Walks et Vivre sa vie, pleinement de Mental Health Matters*, qui sont tous deux présentement utilisés par Autisme Ontario et par la division ontarienne de l'Association canadienne pour la santé mentale, conjointement avec le York ASD Partnership et le SAAAC Autism Centre.

Mental Health Matters—Mood Walks est une série de promenades guidées dans la nature à l'intention des adultes TSA. Ces promenades sont conçues pour encourager et soutenir la santé mentale des participants par l'exercice et en les exposant à la nature. Un « exercice vert », qui consiste à se promener dans la nature, peut avoir des répercussions très positives sur la santé physique et mentale en aidant à composer avec les symptômes de l'anxiété et la dépression. « L'exercice aide les gens à renouer avec la nature et à mieux se sentir, » ajoute Salt.

Salt est également évaluateur du programme *Mental Health Matters—Vivre sa vie, pleinement*. Le programme, qui repose sur les principes de la thérapie cognitivo-comportementale (TCC), fut créé au Royaume-Uni en tant que programme à l'intention des fournisseurs de soins de patients atteints de démence, mais on l'a adapté en Ontario dans une série de huit séances de groupe à l'intention des adultes autistes et de leurs fournisseurs de soins.

> Un « exercice vert », qui consiste à se promener dans la nature, peut avoir des répercussions très positives sur la santé physique et mentale en aidant à composer avec les symptômes de l'anxiété et la dépression.

« Trois séances d'une durée de huit semaines ont eu lieu jusqu'à présent : pour les fournisseurs de soins répartis en deux groupes et une pour les adultes autistes, » souligne Salt. « Tout semblait bien se dérouler. En fait, nous attendons huit nouveaux groupes. »

« Le programme *Vivre sa vie, pleinement* est très avantageux, puisqu'il est abordable, facile à animer et peut se dérouler n'importe où, en milieu urbain ou rural, » dit-il. « Un processus de « formation des formateurs » est en cours afin qu'un plus grand nombre de gens puissent acquérir les compétences nécessaires pour animer les groupes. »

« Nous n'avons pas vraiment beaucoup de programmes pour les adultes TSA, » déclare Salt. « Il ne s'agit peut-être pas de la solution miracle, mais pour les adultes TSA, c'est un point de départ. « Dans la situation actuelle, les adultes autistes souffrent d'une pénurie chronique de services, [et] les enfants autistes deviennent des adultes autistes. »

Apprenez-en davantage sur *Mental Health Matters—Mood Walks* et *Mental Health Matters—Vivre sa vie, pleinement* en consultant le site à l'adresse www.autismontario.com/mentalhealthmatters ■

Bénévolat

LE POUVOIR DE LA COMMUNAUTÉ, DE L'INCLUSION ET DE L'APPARTENANCE

par Laura Heimpel, coordonnatrice des programmes et des bénévoles, région du Centre-Ouest

Définition du besoin d'appartenance : « Désir profond d'appartenir ou de se rattacher à quelque chose de plus grand que soi ».

CHEZ AUTISME ONTARIO, cette définition en dit long sur notre « famille » de bénévoles. Bien ancrée dans les racines qu'elle développe depuis sa création en 1973, notre organisation continue d'apporter un constant soutien aux familles pour tout ce qui touche l'autisme. Notre plus précieuse ressource réside dans les quelques 3 000 bénévoles qui, à la grandeur de la province, facilitent la réalisation de nos programmes et de nos activités.

En tant que coordonnatrice des bénévoles pour Autisme Ontario, le privilège de côtoyer nos bénévoles m'a vraiment enseigné ce qu'est le dévouement, la passion, l'enthousiasme. Nos bénévoles régionaux s'emploient assidûment à élaborer des programmes, à faciliter des activités et à partager de l'information et des ressources avec les familles. Être membre de la communauté autiste donne un grand sentiment de fierté; c'est un excellent moyen d'explorer ses intérêts et ses passions. Chaque jour, je suis reconnaissante de pouvoir collaborer étroitement avec nos bénévoles, avec lesquels je peux approfondir mes connaissances et organiser pour nos familles des activités et des programmes innovateurs.

« Être bénévole, c'est pouvoir exercer un impact durable sur la vie d'une autre personne », explique Jasmeet Chahal, bénévole pour la région Centre-Ouest d'Autisme Ontario. « Mon expérience de bénévolat m'a donné le sentiment d'avoir un but dans la vie—aider les autres. » Tout comme Jasmeet, nos bénévoles aident les familles à profiter d'expériences significatives. Une de nos familles, se remémorant sa récente participation à un programme d'arts martiaux à Halton, nous a déclaré avoir vécu une expérience unique et que sa fille était si fière d'avoir participé à une cérémonie de remise de ceinture, au terme du programme, qu'elle tenait à montrer sa ceinture à tous ses amis. Des moments comme ceux-ci sont vraiment spéciaux pour la communauté autiste, et pour les bénévoles qui soutiennent ces programmes et activités.

Notre réseau de bénévoles est composé d'étudiants, de parents ou de frères et sœurs d'enfants TSA, d'adultes TSA, d'auto-représentants, de professionnels, de futurs travailleurs sociaux, de futurs professionnels de l'ACA et d'alliés de l'autisme. Les bénévoles s'impliquent dans diverses initiatives, notamment l'action revendicatrice, la sensibilisation, les activités, les programmes, les prélèvements de fonds, et bien d'autres encore.

« De plus », ajoute Jasmeet, au sujet de son bénévolat chez Autisme Ontario, « j'ai glané au fil du temps de précieuses compétences et connaissances. J'ai appris à devenir plus patiente, plus compréhensive et plus active dans ma communauté, et j'ai acquis une vision du monde plus holistique. Une des leçons les plus précieuses que je retire du bénévolat, c'est de ne jamais juger un livre par sa couverture, car chaque personne mène des combats dont son entourage n'a pas idée ».

En songeant aux efforts collectifs que nous avons déployés en 2019, je ressens une profonde gratitude envers chacun et chacune des bénévoles qui font de notre organisation une communauté vraiment inclusive!

Joignez-vous à notre « famille » et découvrez ce que signifie faire partie de quelque chose de plus grand que soi. Contactez votre section locale pour en apprendre davantage sur la façon de contribuer, et pour indiquer comment vous aimeriez contribuer!

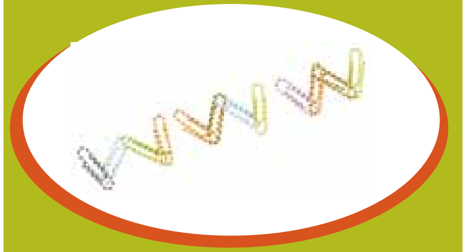
Coup de karaté : *Arts martiaux adaptés Notre section de Halton tient à remercier l'Academy of Martial Arts de South Oakville pour sa participation au programme d'arts martiaux adaptés, qui a accueilli plus de 30 enfants et adolescents TSA depuis le début de 2019! Un grand merci à Sensai Mai Salhia et à son équipe du studio, qui offrent cet excellent programme aux familles.*

Le programme d'arts martiaux adaptés d'une durée huit semaines, automne 2019, à South Oakville

Relations communautaires

Jamie Read, Kelsey McDaniel et Hayley Stolarchuk, prestataires des services de navigation d'Autisme Ontario, participent à la célébration des Fêtes, une activité bilingue à Ottawa.

Photo crédit : Kelsey McDaniel



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 ».

Webinaire en direct:

DIVULGATION DES BESOINS, RECHERCHE D'EMPLOI ET SOCIALISATION AU TRAVAIL (EN ANGLAIS)

Jeudi 16 avril 2020

De 19 h 00 à 20 h 00

Sarah Southey est une travailleuse sociale (M.S.S.) qui a à son crédit plus de 12 années d'expérience pratique auprès des adolescents et des adultes ayant un TSA, un TDAH, des troubles d'apprentissage ou des problèmes de santé mentale.

Êtes-vous un adolescent ou un jeune adulte TSA qui a un emploi ou qui en recherche un? Cet atelier vous apprendra des stratégies pratiques sur les aspects suivants :

- Comment et quand faire part de vos besoins supplémentaires sur le lieu de travail
- Comment chercher un emploi plus efficacement
- Comment gérer le volet social au travail

INSCRIVEZ-VOUS AUJOURD'HUI

bit.ly/AutismEmploymentWebinar

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Dr. Mackenzie Salt presenting at the 38th Annual Meeting of the Atlantic Provinces Linguistic Association, 2014 Photo credit: Anthony Lister

ASD and Mental Health

PROGRAMS TO HELP AUTISTIC ADULTS, FAMILIES AND CAREGIVERS

by Michael Cnudde

Early in his academic career as a researcher, Dr. Mackenzie Salt found issues in early studies of autism. These studies, he said, had problems with reproducibility—central to the peer review process—and those that were able to be reproduced were still flawed.

"WHAT PREVIOUS STUDIES HAVE DONE with children is they have paired a child with an adult, who looked like an authority figure to the child," said Salt. "This created a power imbalance where the child might simply be trying to please the adult."

The fact that these studies always involved children, and no adults, on the autism spectrum, also concerned him.

Salt, who earned his PhD at McMaster's Cognitive Science of Language program in the Department of Linguistics and Languages, felt something was missing. In his doctoral dissertation, *Deficits or Differences? A New Methodology for Studying Pragmatic Language in Autism Spectrum Disorder*, he developed a new methodology based on observing individuals on the spectrum interacting with others in a naturalistic setting, in order to make conclusions about how autistic people interact in everyday life. His study was the first to look at communications between adults on the spectrum. As a person with Autism Spectrum Disorder (ASD), Salt found his research especially meaningful. “I wanted to see my research help people,” said Salt. “I wanted to help people now and see the work I did have a direct impact on my community.”

Salt, currently an independent contractor and researcher from the McMaster University Autism Research Team (MacART) who is also serving as a Program Evaluator for Autism Ontario, is working with the Public Health Agency of Canada (PHAC) to evaluate two programs that assist adults, adolescents, their families and caregivers: *Mental Health Matters—Mood Walks*, and *Mental Health Matters—Living Life to the Full*, both currently in use by Autism Ontario and the Canadian Mental Health Association (CMHA) Ontario Division in conjunction with the York ASD Partnership and SAAAC Autism Centre.

> A “green exercise”—taking nature walks for fun—can yield significant positive effects on physical and mental health, helping to deal with symptoms of anxiety and depression.

Mental Health Matters—Mood Walks is a series of guided nature walks for adults on the spectrum. The walks are designed to encourage and support the mental health of participants through exercise and exposure to nature. A “green exercise”—taking nature walks for fun—can yield significant positive effects on physical and mental health, helping to deal with symptoms of anxiety and depression. “The exercise helps people reconnect with nature and feel better,” said Salt.

Salt is also the Program Evaluator on *Mental Health Matters—Living Life to the Full*. The program, based on the principles of Cognitive Behavioural Therapy (CBT), originated in the UK as a program for caregivers of dementia patients, but has been adapted in Ontario as a series of eight-week group sessions for both autistic adults and caregivers of autistic adults. “We’ve had three eight-week sessions run so far: caregivers in two groups, and one for autistic adults,” said Salt. “It’s tended to go pretty well. In fact, we have eight more groups coming up.”

“The great advantage is that *Living Life to the Full* is low cost, easy to conduct, and can be done anywhere, in an urban or rural setting,” he said. “We have a ‘train the trainer’ process under way so that more people can be qualified to lead the groups.”

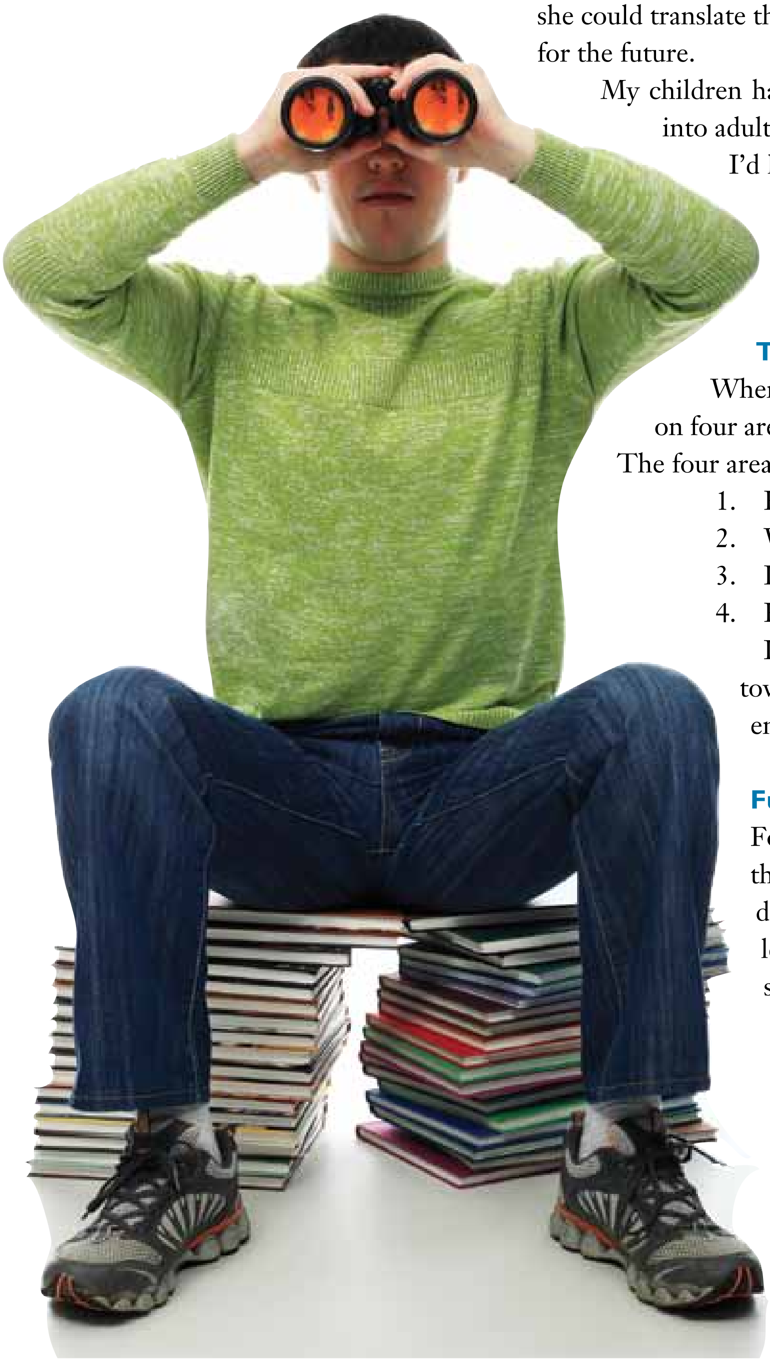
“We don’t really have a lot of programs for adults on the spectrum,” said Salt. “It may not be the be-all and end-all, but for adults on the spectrum, it is a place to start. As it stands now, adults with autism are chronically underserved, [and] children with autism grow up to be adults with autism.”

Learn more about *Mental Health Matters—Mood Walks* and *Mental Health Matters—Living Life to the Full* at www.autismontario.com/mentalhealthmatters. ■

Autism x 2: Transitioning into Adulthood

THE FUTURE IS BRIGHT

by Maureen Bennie



BigStockPhoto.com

A FEW YEARS AGO, I wrote a post about the experience of raising my two children with autism. I first wrote this piece from the point of view when my son and daughter were quite young. Recently, someone from China contacted me to ask if she could translate the post because it would encourage families and give them hope for the future.

My children have been out of school for almost two years now and are well into adulthood. Marc is about to turn 22 and Julia will be 20 next month. I'd like to share where we are now because when your children are younger, it's hard to imagine what the future will be like for them. You feel like things will never change or improve and you can't see the results of all your efforts.

Transitioning to Adulthood

When I was creating a transition plan for Marc and Julia, I focused on four areas to keep myself from becoming overwhelmed and unfocused. The four areas were:

1. Further Education
2. Work Opportunities
3. Leisure/Recreation
4. Free time

I kept in mind that all four of these areas could help build skills toward independent living, create a sense of well-being, and add to enjoyment of life.

Further Education

For further education, I looked at continuing education courses, the public library (lots of free offerings), courses for people with disabilities at a small university, community-based classes, and lectures offered around the city. I was able to piece together some great courses that furthered the interests of Marc and Julia.

Some examples are:

- computer courses
- first aid
- health and fitness
- tutoring in math/reading
- music and art

My son has always enjoyed the school setting, so he really wanted to continue learning in an academic environment.

Julia was more reluctant, but in the end was willing to try because I showed her how university was a lot different from school. She didn't have to stay all day and there were restaurants all over campus. This intrigued her and was enough to motivate her to try one course per semester.

Work Opportunities

In the area of work, I started very early and had the kids volunteer at a local farmer's market once a week from the time they were 11 and 13. The shifts were three hours long and the environment was a gentle one (outdoors, no loud music or confined spaces). It has been a great success and taught them a lot. They learned to report to a manager and wear a uniform. No tech devices were allowed during work, and they each had job descriptions with tasks to fulfill. Their independence had grown so much that they needed very little supervision at this job. The added bonus is my son now has this huge diet of fruit and veggies which I believe was from repeated exposure to these items in a gentle, non-overwhelming environment. Marc used to eat less than 15 foods until the age of 16.

Julia had a dream of working with cats, so we got involved with the Meow Foundation when she was 14. You have to be 18 to volunteer with them. I made sure Julia became familiar with all aspects of their organization for four years by attending their adoption days, fundraisers, pet store visits, sponsoring cats every Christmas, and we adopted a cat from them as well. When Julia turned 18, she was able to do a great interview, with my support, for the volunteer coordinator. I think Julia's ability to do all of the cat facial expressions from their website list of cats they had over the years impressed her the most.

Because Marc likes formal learning situations, we had him attend several sessions of Ready, Willing and Able. He loves movies and was given a work experience for five months at a movie theater close to our home. He excelled at this job and is waiting to hear if he will get a permanent paying job.

Both kids volunteer twice a week at an autism society that has a local food bank that only services families/individuals with autism. They create the shopping list, do data entry, shop for the groceries every week, and then have to put them away into the correct categories. Lots of life skills being learned there in a real environment!

Leisure/Recreation

I know from my work in the Low Arousal Approach that regular physical activity is important for keeping anxiety at bay. We have our kids swimming, bowling and working out three times a week.

Because Marc likes organized classes and being with a group, he also has a dance class, attends yoga, horseback rides, and he recently added Aquacize. That has been wonderful for him because it combines his love of the water with music.

Julia takes a painting class once a week with a community group. She has done very well and recently had a month-long show which earned her some money to put towards a trip she wants to take. She didn't want to do the art show, but once she had some motivation, she jumped on board.

Julia also takes a cooking class once a week and has a home baking program two days a week. I've now added errands to her list twice a week like picking up a few groceries, getting items at the library, and taking the bottles back. She gets to keep the money but once a month, she has to use the money to buy supplies for the cats at the Meow Foundation as they have an ongoing wish list of donations that they need.

Free Time

When it comes to free time, the kids have both shared and different interests. They play Wii games together on the weekend and both love looking up things that interest them on YouTube. Marc is an avid reader and reads aloud to himself about three hours a day. His books of choice are adult non-fiction. He also likes to meditate to classical music once a week for an hour in his room. On weekends, the kids go to films, plays, dance recitals, library lectures and concerts.

This may sound like it all costs a fortune, but it doesn't. I applied for something called a Fair Entry card that offers a greatly reduced entrance fee for all city recreational facilities. I found out that if you go the symphony box office an hour before the program starts, you can get tickets for just $25 rather than $90. We also have an Access 2 card that allows two-for-one entries to many venues around the city and across Canada.

I would encourage you to contact your local autism society or disability resource centre for information on how to access opportunities for free or at a reduced price. Local libraries offer so much as well and are huge community hubs for all kinds of activities.

Final Thoughts

Although our entry into adult services was a very rough and scary one, things are going well now that the initial adjustment period to such a huge change from school is over. I see great development and learning continuing for both Marc and Julia, and they are both happy and healthy. They still remain the best of friends but are also spreading their wings doing things apart that they love and coming together for the activities they like to do together, like swimming. I could never have guessed when they were little that their lives would turn out as well as they have. It's been a lot of hard work and planning, but it has paid off.

Keep at it because it is hard to imagine the future for your children and what they will be like when they are little. If you give them a good foundation in a variety of areas, it will serve them well as adults.

Reprinted with permission. This article first appeared on the Autism Awareness Centre's Articles & Blogs on February 4, 2019. (https://autismawarenesscentre.com/).

StoryBlocks.com

The Right Play

DEVELOPING LEISURE ACTIVITIES FOR INDIVIDUALS WITH ASD

by Maureen Bennie

LEISURE ACTIVITIES are an important part of life for everyone. Engaging in activities that are fun, enjoyable and interesting increases a person's well-being, happiness and satisfaction in life. Leisure activities can be done alone or in a group, at home or out in the community. We learn activities by watching others, taking lessons, joining clubs, reading instructions, or simply by trying.

For people with ASD, developing leisure interests and skills can be more challenging because skills are often not learned through informal observation of others or through imitation. Their interests are developed in their own way. How to use materials may not be understood and the materials may be primarily used for their sensory qualities. Skills learned through one activity may not be generalized to another.

Why is developing leisure skills important?

Challenging behaviours are often reduced when a person engages in personally satisfying leisure activities. The ability to entertain oneself can reduce stress for the individual both at home and in the community.

There are also social benefits. Leisure skills and interests can connect individuals who share the same passion. An activity brings a group of people together who share an interest and like to talk about it. My son Marc loves drumming so he regularly attends drum circles. He connects with others who enjoy drumming and they all play music together.

Exposure to a wide variety of activities and experiences broadens interests. Interests will also change over time so it's important to keep expanding experiences for growth and development.

Making leisure materials and activities more successful

While everyone has personal preferences, the following specific qualities can make activities more meaningful and successful.

Understandable

Understanding an activity, the purpose of materials and what to do with them can sometimes be difficult. Some ideas to make things more understandable are:

1. Clear, static rules
2. Well-defined beginning and end
3. Predictable or repetitive quality
4. Clear visual representation of what to do
5. Minimal verbal instruction
6. tructured activities

Reactive

Reactive materials provide reinforcement through sensory feedback. This means that when you do an action, something happens and it looks different. Examples are lights, sounds, movement and tactile sensation. Electronic and computer games provide this kind of feedback, although it can be a struggle to limit time on tech devices. Music can add interest as well.

Comfortable

Qualities that can increase comfort level are:

1. Challenging without being over-stimulating
2. Suitable for the person's ability level
3. Limited demands for complex social interaction
4. Opportunity for a sense of control or mastery

Active

Young children need activities that use gross motor skills such as climbing, running and jumping. Rhythmic activities such as swinging or swimming are also good choices.

No matter what age an individual is, they need physical activity to help reduce stress, build muscle and increase flexibility and balance. Regular exercise can also contribute to a better night's sleep.

Visual-Spatial

Repetitive manipulation of objects, putting things in order, or fitting objects into spaces can be very motivating. There are lots of toys and games that provide these qualities, such as puzzles.

How Can We Find Out What A Person Likes to Do?

In the book, *Developing Leisure Time Skills for Persons with Autism*, the authors recommend creating a Leisure Lifestyle Profile. The profile information is gathered through a parent/caregiver interview, an interview with the individual and direct observation assessment, followed by an assessment of the leisure and sensory preferences of the individual.

It's also important to assess what family and friends like to do as they often provide the expanded opportunities for activities. In our family, my son Marc loves audio tours, so we visit historical sites and museums that provide audio guides. Marc will spend hours looking at paintings if he can press a button and listen to the stories about them. He does not have the same level of interest without the audio guide.

Some families like sports, concerts, nature walks, cooking, travelling, historical sites, gyms—the list is endless. By doing activities that the family likes to do, there will be more opportunities for the person with ASD for practice, engagement and skill building.

Expanding interests

I've written on this topic before and it's an important one. As a person ages and matures, their interests will change. Boredom can become a problem over time. A person can also get "stuck" in an activity and way of doing things.

Greater independence is achieved through being able to do activities across a variety of environments. My daughter Julia loves cooking, particularly baking. She has an at-home baking program and also attends a cooking class once a week. Our next goal is to get her volunteering at an organization that makes meals for mothers in need. This will give Julia's cooking a broader, community-based purpose and connect her to new people. She also volunteers once a week at a farmer's market to get exposure to raw ingredients and homemade products.

Leisure activities connect us to our family and community. They develop skills, increase independence and reduce stress. Greater life satisfaction fosters happiness and well-being, and when a person is happy, they are generally more flexible and adaptable—both important life skills.

Reprinted with permission. This article first appeared on the Autism Awareness Centre's Articles & Blogs on August 13, 2018. (https://autismawarenesscentre.com/)

Autism Ontario Bilingual Services

Jamie Read, Kelsey McDaniel and Hayley Stolarchuk, Autism Ontario Service Navigators participate at a holiday party, a bilingual activity in Ottawa.

Photo crédit : Kelsey McDaniel

Photo courtesy Courtney Weaver

Part 4 of 4

My Affectionate, Loving and Fun Grandparents

THE DYNAMICS OF A FAMILY WITH THREE CHILDREN, TWO OF WHOM ARE ON THE SPECTRUM

by Courtney Weaver, Self Advocate

MY MATERNAL AND PATERNAL GRANDPARENTS will be the focus of my final article about how autism has affected the dynamics of my immediate family.

The relationship my grandparents have with the rest of my family (me, my sisters Ashley and Serena, Mom and Dad) is a warm, loving and understanding one that is also filled with respect and admiration. The years after Ashley and I were diagnosed were certainly a learning curve for my grandparents. Mom and Dad were the ones who had to teach their parents about autism from what they had learned in their research and in caring for me and Ashley.

Admittedly, there was an early period when one set of my grandparents was wondering whether Ashley and I would ever be “fixed” when they heard our diagnosis. But that is long gone now.

When they were asked during the writing of this article if they wanted a so-called normal family, their answers, while slightly different, both reflected that they view Ashley and me as part of their "norm" and part of the family fold.

Their answers vary on what it is about autism that more people need to be aware of. One set of grandparents stated that societal understanding needs to increase. Such understanding needs to include the realization that no two persons diagnosed with autism have the same talents, skills or characteristics. Meanwhile, one of my grandmas is optimistic that understanding about autism will grow because more people are getting impacted by it due to increased diagnosis rates. One of my grandpas hopes that the cause of autism will be discovered and that resources and information will be available to assist families who are impacted by autism. One thing that is common in all their views is that understanding of autism needs to increase.

As my social confidence and ability to connect to other people have increased over the years, I've gotten closer to my grandparents. When I first encountered them roughly 24 years ago, I would not go over and hug them but would cling close to my mom instead. I didn't want them coming over and giving me affection or talking to me either. As my awareness has changed, so has theirs, I'm now on a nickname, sharing puns and hugging level with each of them.

Connie, almost 95 years young—otherwise known as Oma—my paternal grandmother, loves reading, writing and maintaining communication with distant and close family members and friends. She loves to do what she calls *volunteerism* from home where even though she isn't really physically active, she still does little things to reach out to others to let them know that she is thinking of them, whether they are going through pleasant or tough times. Participating in church activities is profoundly important to her as well.

Alex, 92 years young—also known as Opa—my paternal grandfather, has always had an interest in the outdoors, with fishing as his favourite activity. He enjoyed travelling later in life. Even though he really can't do those things anymore, he reads about them and enjoys seeing new equipment and conveniences. He also loves telling stories from his earlier life in different parts of British Columbia. Both Oma and Opa also enjoy any family outings (whether with my Mom's parents, their sons, Mom, me or any of my sisters) very much.

My maternal grandpa, Lorne, almost 78 years young, is a prankster who likes to give little foot taps to family members to show he loves them. His favourite exclamation is, "Lucky skunk!" Whenever he gives me a foot tap, I say, "Grandpa!" and he innocently looks and says, "What?" Silly Grandpa! He has the most teasing relationship with me out of all my grandparents. He loves time with the family, reading and outdoor activities.

My maternal grandma, Rose, 73 years young, absolutely loves cooking for the family. My favourite dessert is her angel food cake which is so light and perfect with vanilla ice cream, raspberries and some hard caramel icing. Ashley's favourite dessert is Grandma's soy chocolate pudding pie topped with whipped cream, and Mom's favourite is her apple pie with a slice of cheese. Grandma also loves going for walks and car rides with Grandpa, visiting family and friends, having lunch with friends and enjoys a little after-lunch gambling at the casino. She also loves laughing and her pet peeve is people who say they can't do something before they try.

I'm immensely grateful to have both sets of grandparents still in my life as I approach my 28th birthday. Although I did not want to be close to them when I was young, I have learned to be more open and accepting and they have been patient. We've learned from each other and I look forward to more years together. ■

Photo credit: Shelly Cameron

A Loss for the Autism Community

AUTISM ONTARIO is saddened to announce that we recently lost one of our leaders. Marilyn Thompson had been struggling with cancer and on February 26, 2020 she passed away with family and friends at her side. Marilyn began her work with Autism Ontario 13 years ago and was most recently the Director of Family Supports and Programs. At that time she was instrumental in implementing a brand new *Realize Community Potential Program* and in overseeing its successful expansion to the province-wide *Potential Programme*. She also served as a volunteer on the Board of the local Children's Aid Society in her community. Our heartfelt condolences go out to her son Tyler, her family, her co-workers and friends. She will be missed by many whose lives she touched. ■

A Mother's Reflection

ON THE DAYS I FEEL LIKE I'M NOT DOING ENOUGH

StoryBlocks.com

by Maria Garito

TODAY IS ONE OF THOSE DAYS. The days where my thoughts take over and tell me I'm just not doing enough. That my son isn't doing well, and it's because I haven't given him what he needs.

It's hard enough being a parent in this fast-paced world of juggling the impossible, but parenting a child with autism comes with an entire set of expectations I am nowhere near mastering.

Today I'm asking myself if I'm making the right decision to send him to school.

- Am I advocating enough?
- Am I pushing him too hard to be part of a system that wasn't made for him?
- Am I disrupting his consistency by pulling him out of school for therapy?
- Is the therapy helping?
- Is he tired?
- Does he need a break from it all?

And when your child is non-verbal, every decision you make on their behalf becomes a game of trial and error. I can't ask him what he thinks, because he can't let me know beyond the few basic requests he makes in relation to food and some activities.

I long for the day when he is able to tell me what he did at school or can tell me how he feels. I would do anything to connect my brain to his brain so he could relay messages to me about how he sees the world.

And I see him trying. Trying to communicate with me. And I interpret. I interpret his mood, his reluctance to get in the car, his smile when I'm putting on his boots. I see how happy he is when he skips into his therapy centre and waves bye to me. I see how easily he enters the play yard at school and runs to the play structure, all while looking back to see me smiling at him. I see how thrilled he is when we get ready to take a drive in the car, as he flaps his hands and jumps for joy.

Then I'm calm again. Then I remind myself that even if I'm not enough in my mind—to my son, I am everything.

And even if he can't tell me that things are going well, he does let me know he loves me through his smile, hugs and kisses.

And maybe for today, that's enough. ■

Originally published on www.themighty.com

Volunteerism

THE POWER OF COMMUNITY, INCLUSION AND BELONGING

by Laura Heimpel, Regional Program and Volunteer Coordinator, Central West Region

Definition of *belongingness*: "To feel an inherent desire to belong or connect to something greater than themselves."

THIS DEFINITION OF BELONGING speaks volumes to the "family" of volunteers which Autism Ontario supports. Building on our roots since inception in 1973, Autism Ontario has stayed true to supporting families on all autism-related issues. With over 3,000 volunteers supporting programs and events across the province, our volunteers are our most valuable resource.

Working as a Volunteer Coordinator for Autism Ontario, I've truly learned what dedication, passion and enthusiasm look like from our volunteers. The network of volunteers in our region work diligently to build programs, volunteer at events and share information and resources with families. They feel a sense of pride in being a part of the autism community and it's a great way to explore their interests and passions. Each and every day, I am thankful to work closely with our volunteers to learn more and build innovative programs and events for our families.

"Volunteering means being able to create a lasting impact on another person's life," says Jasmeet Chahal, a volunteer with Autism Ontario Central West. "My experience with volunteering has instilled a sense of purpose in me to help others." Volunteers like Jasmeet help encourage and support these meaningful experiences with our families. One of our families recalls her experience at a recent martial arts program in Halton. She stated that this experience was one-of-a-kind, and that her daughter was so proud to experience a belt ceremony at the conclusion of the program, showing it off to all her friends. Moments like these are special for the autism community and the volunteers who help support these programs and events.

Our network of volunteers are students, parents or siblings of children with ASD, adults with ASD, self-advocates, students, professionals, future social workers, future ABA professionals, and autism allies. Volunteers are involved in a number of initiatives including advocacy, awareness, events, programs, fundraising and much more.

"Additionally," says Jasmeet, as she reflects on her volunteer work with Autism Ontario, "I have gained valuable characteristics and knowledge over time. I have learned to become more patient, more understanding, more active in my community and more holistic in my perception of the world. One of the most valuable lessons volunteering has taught me is to never judge a book by its cover, because we are all fighting battles unknown to those around us."

As I reflect on our collective efforts in 2019, I am truly grateful for each and every volunteer who has made our organization a truly inclusive community.

Come join the "family" and experience what it means to feel part of something greater. Contact your local chapter to learn more about getting involved, and how you'd like to contribute. ■

Karate "Chop" Adapted Martial Arts
Our Halton Chapter wishes to thank Academy of Martial Arts South Oakville for their partnership in offering adaptive martial arts programs. Since early 2019, this program has seen more than 30 children and teens with ASD participate. A huge thank you to Sensai Mai Salhia and her team at the studio for delivering such a great program for families.

Live Webinar:

DISCLOSURE, JOB SEARCHING & BEING SOCIAL AT WORK

Thursday April 16, 2020

7:00p.m.- 8:00p.m.

Sarah Southey is a Social Worker (M.S.W.), with over 12 years of experience working with adolescents and adults with ASD, ADHD, learning disabilities and mental health issues.

Are you a youth or young adult on the spectrum who is employed or looking for employment? This workshop will provide you with practical strategies:

- How and when to disclose additional needs in the workplace
- How to job search more effectively
- How to manage the social component at work

REGISTER TODAY:

bit.ly/AutismEmploymentWebinar

AutismONTARIO

OAP Provider List

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

LA LISTE DES FOURNISSEURS est hébergée par Autisme Ontario et disponible sur le site oapproviderlist.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.

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