

April 1, 2011

Issue 23

Parent Reflections on Raising a Child who has an ASD

Inside this issue:

Community Corner	2
Communication Corner	2
Hot off the Press!	2
Behavior Tip	2
OT corner	3
Fitting In	3
www	3
Try this!	4
Coming Soon!	4
Read All About It!	4

As educators, we strive daily to help our students reach their full potential. This challenging task is often even more difficult when we consider our students who have an ASD because of the varying expectations from the people in their lives. Although each case is individual, this article features some personal reflections from parents of children who have an ASD compiled by our team.

“We want what is best for our kids”

Like all parents, parents of children who have an ASD want what is best for them. This includes their children being happy, having a bright and productive future, and becoming independent. Although there is no manual on how to achieve this for any child, parents of children who have an ASD are faced with nearly an alphabet’s worth of options (i.e., ABA, PECS, RDI, TEACCH, OT, etc.), each with its own set of promises and demands. Making a selection is no small feat. For us as educators, looking from the outside, it is sometimes apparent that a certain therapy or treatment option is not working. However, parents do not have this opportunity to look at things from the outside. As one parent stated, *“I chose to become a parent, not an autism expert. So I have no idea how to make sense of what is out there. So it’s all about trial and error, and asking lots of questions, and keeping my fingers crossed.”* Similarly, another parent explained, *“As a parent, you want to make things right. When my son first got diagnosed, I tried to do anything and everything to make him better. If someone had told me that having him sleep on his head and eating liver everyday would cure him, I would have done it. I honestly would have. I can look back now at the things that I did and laugh but it took me a long time to get there. It’s not that we’re crazy, it’s that we are desperate!”*

“Our biggest fears”

Often with much emotion, every parent interviewed expressed that their biggest fear was what would happen to their child when they were no longer around. Who would advocate for them? Who would ensure that they were not being hurt? Who would love them unconditionally? Although these were expressed as long-term fears, it was clear that these same concerns affected the parents’ ongoing interactions with the school. Behind the distrust and dissatisfaction sometimes directed by parents to schools was an underlying anxiety about people giving up on their child, not having high enough expectations, or having their child get lost in the shuffle. The parents described how they felt that they could not let their guard down.

“What parents want us to know”

Several recurring themes emerged when parents were asked what message they would like to share with educators. A few parents quickly mentioned the names of guardian angels who had come into their lives as a result of having a child with an ASD. They expressed gratitude for these individuals. This led to the parents explaining that, although they may not always have seemed like it and may not have said it often enough, they were thankful for the care and support that they received from school professionals and support staff.

The importance of regular and honest communication was also identified by parents as something they would like to pass along. The parents expressed how much they needed to know what was going on in the school. This knowledge decreased anxiety about the unknown, allowed for better collaboration with private therapists, and helped them to gain insight about what was happening during their child’s day.

Conclusion

Thank you to all the parents who agreed to be interviewed and who spoke so candidly about their experiences for this article. Thank you for increasing our awareness about the daily practical and emotional struggles of raising a child who has an ASD. Thank you for reminding us to have empathy and to give you reasons to regularly celebrate your child. Thank you for your trust and support! Jade Lawsane



ASD Team Members:

- Dr. Andrew Bennett
Psychologist /Co-coordinator
- Jovette Francoeur
Special Needs Consultant/ Co-coordinator
- Patricia Assouad
ASD Consultant
- Sabrina Gabriele
ASD Consultant
- Joëlle Hadaya
Occupational Therapist
- Leigh-Ann Jones
ASD Consultant
- Helene Packman
Speech & Language
Pathologist

Community Corner:



This year, for the first time, Montreal is launching a Walk Now fundraiser. This inspirational event was created by Autism Speaks, North America's largest autism science and advocacy organization. Walk Now is an extraordinary effort to raise money to fund research and to provide support for family services programs. Across cities in North America, groups of devoted educators, families, researchers, and corporate teams unite to participate in this exciting activity, and walk for autism. This event continues to raise awareness in the community and across nations. For its first year, Montreal is determined to raise \$200,000! So far, over \$20,000 has been raised. The walk will take place on Sunday June 19th at the Stade Uniprix. To walk for a cause, or to make a donation, go to: <http://www.walknowforautismspeaks.ca>

So, make this first event a memorable one; Walk Now Montreal!

Communication Corner

The use of visual supports helps students understand what to expect in the classroom. They also assist the student in making transitions from one activity to another. When students understand what is expected of them, behaviour difficulties are reduced and independence increases.

There are several interesting websites that provide ideas and readymade materials for using visual supports:

Use Visual Strategies to Support the Communication Needs in Autism: <http://www.usevisualstrategies.com/Welcome.aspx>

This website contains information for visual strategies along with some free printable pictures. A recent contest was held to encourage readers to share ideas for using visual strategies. These ideas can be viewed and downloaded to your computer and may inspire you to use some of these ideas yourself. Follow the link from the homepage to view the winning entry.

The Geneva Centre for Autism: <http://autism.net>

This website provides a wealth of free visual tools that you can print. There are also video demonstrations as to how you can implement each tool. Both French and English resources are available. These visuals can be found by following the link to the Visual Gallery at the bottom of

the homepage or directly at: <http://elearning.autism.net/visuals/main.php>

Sen Teacher : <http://www.senteacher.org/Worksheet/6/PECS.shtml>

This website is a free website that provides photo cards that can be used to teach vocabulary and can be used for AAC systems as well. Pictures are organized into categories and you can change the wording and pictures to best meet the needs of your students.

The Down's Syndrome Association: http://www.supportdisc.co.uk/Visual_timetable.htm

This website is from the United Kingdom but provides a free download to help you create daily and weekly schedules.

Mrs. Riley: <http://mrsriley.com/home>

This website is a complete picture gallery website that allows you to easily make picture cards for schedules or learning. Although there is a fee to use the website, a free trial is available.

Hot off the Press!

In her book, « Now I See the Moon » Elaine Hall speaks honestly and poignantly about the challenges and gifts of raising a child who has autism. This is an emotionally powerful story that will give professionals a rare look into the realities of autism from the home front. Elaine Hall is also the musical and artistic director of the Miracle Project, a theatre arts project for children who have an ASD which was made into the Emmy Award-winning documentary Autism: The Musical.

Behaviour Tip

Research in autism indicates that consistency is one of the key elements in teaching and developing appropriate behaviours and skills in students with an ASD. Consistency in the use of strategies and in the use of language has proven to be even more important when there are several adults working with the same child, including school staff members, parents, and home educators.

School and home collaboration has always been a goal that is identified and encouraged in order to increase a student's chance of success, since it creates the consistency that is so essential to progress. This collaboration can take on many forms. For example, the use of visual supports is a common strategy used in our schools because it fits so well with the learning style of most students with an ASD. A variety of visual schedules, cue cards, and positive reinforcement charts are used on a daily basis to ensure the structure and predictability of the school day. They also help the students better understand and internalize the skills we are trying to teach them. The goal of internalization is furthered by parents using the same strategies at home as a way to structure the student's day even further. Of course, the reverse is equally true. If there are successful strategies used at home, the school team, in consultation with parents and home educators, should also try to incorporate the same methods into the school program. IEP meetings represent an ideal venue for sharing, as they provide an opportunity for an active exchange of information between all partners. In the end, as long as the lines of communication between home and school remain open, collaboration can lead to great results!

Occupational Therapy Corner

Emphasizing functional independence of individuals with an ASD is one of the cornerstones of successful inclusion and future quality of life. In order to ensure autonomy in future life skills, participation in domestic tasks should be introduced from a young age. Even though independent performance may be the targeted goal, many other foundational skills such as motor planning, problem-solving, sequencing, attention to detail, and concentration are also reinforced during the teaching and practice of domestic tasks. These underlying skills support school achievement and lifelong learning. Specific domestic tasks also provide much needed sensory input, and are therefore often included by the occupational therapist in the students' Sensory Diet at school and home. Keeping in mind your student/child's developmental abilities, the following is a short list of common functional tasks to consider when putting together his/her daily schedule.

At School:

- **Recycling and garbage chores:** Carrying, pushing and emptying recycling bins and garbage cans (muscular effort) provides proprioceptive calming as well as organizing input.
- **Putting chairs up or taking them down from desks or tables in the library or classroom:** This repetitive physical task, in addition to providing calming and organizing input, works on spatial awareness and organization of the physical environment.
- **Classroom chores, such as being the milk or supply attendant:** These tasks involve counting, sorting, distributing and social skills which support learning in an inclusive setting.
- **Organizing mats in the gym:** Pulling, folding and stacking the mats in the gym works on motor planning, spatial relations, sequencing and endurance.
- **Sweeping the lunchroom:** Performance components of this task include spatial awareness, organization of movements, concentration and attention to detail.
- **Cleaning desks or lunch tables using a spray bottle (soapy water) and sponge:** This task involves bilateral integration, coordination and attention to detail.

At Home:

- **Setting the table:** Providing a visual such as a paper placemat with dishes and cutlery drawn in appropriate location and preparation of dishes on counter, as needed.
- **Washing and drying the dishes or emptying and putting away dishes from the dishwasher:** Practice washing plastic cups, plates and cutlery initially. These tasks work on visual-spatial memory, manipulative skills, sorting and upper extremity strength.
- **Sorting/matching socks and folding clothes:** These tasks emphasize in particular visual discrimination, spatial relations, motor planning and sequencing skills.
- **Cooking or preparing snacks:** Following steps of a recipe to prepare a snack or a simple dish involves motor planning, sequencing and math skills (quantity/measuring).
- **Vacuuming:** If the child can tolerate the noise, maneuvering a vacuum cleaner could be calming as a result of the vibration, rhythmic movement and proprioceptive input.
- **Shoveling snow:** This task requires muscular effort and endurance and works as a great energy outlet.

Don't hesitate to use visual strips of steps to follow, checklists, calendar of weekly chores, a reward system and/or a timer as needed, when teaching the tasks and to promote independent performance once motor and cognitive components of tasks are mastered.

Joelle Hadaya, erg

Fitting In: Social Skills Training

[www](http://www.autismfamilyonline.com)

From October 2010 to February 2011, John Rennie High School and Lindsay Place High School took part in our second session of the **Fitting In: Social Skills Training(FISST)** program. The group consisted of six students with an ASD and six neuro-typical peer tutors. They were enthusiastic participants and thoroughly enjoyed being part of the group. Students learned the social skills through role-play, modeling, and discussion activities. Some of the topics covered were conversation skills, making friends and maintaining friendships, bullying, and joining a group. Three evening outings, outside of the school setting, allowed the students to practice their newly acquired skills. Feedback from staff and parents has been very positive in that they have enjoyed watching their students and children gain confidence and make friends. Overall, **FISST** was a success. Students with an ASD made notable improvements through practicing social skills, and are now able to generalize many of these skills across different contexts. The peer tutors gained understanding about individuals with ASD and the social difficulties they encounter on a daily basis.

AutismFamilyOnline.com is a worldwide group of family members, therapists, educators and others dedicated to meeting the practical, every day needs of individuals with Autism Spectrum Disorders. Join this group to gain valuable information, get answers to your pressing questions and much, much more. To receive a weekly tip of the week by e-mail from Autism Family Online, go to www.autismfamilyonline.com and sign up.



Lester B. Pearson School Board
1925 Brookdale Avenue
Dorval, Quebec
Phone: 514-422-3000
Fax: 514-422-3014
E-mail: abennett@lbpsb.qc.ca

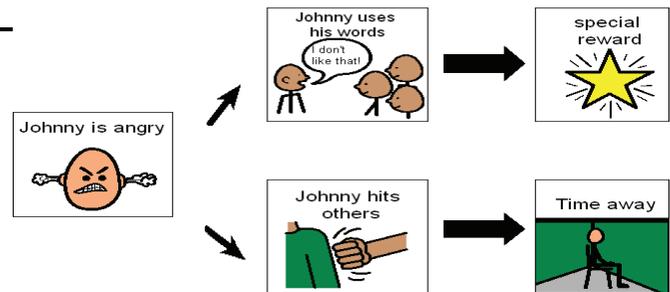
Our team is comprised of several professionals with a variety of specializations. Designated as a Centre of Excellence within the province, our mandate is to assist LBPSB schools in the implementation of best practices for the inclusion of students with an ASD and to serve as a resource to the other English school boards in Quebec. Our team provides assistance to students and families and works to support educational personnel in augmenting their capacity to meet a wide range of needs in the classroom. We do this through direct intervention, coaching, consulting, professional development, and the sharing of materials.

We wish all the best to two of our ASD Consultants: Congratulations to Jade who is on leave, expecting the arrival of her third child (who may have arrived as this goes to print). Congratulations to Leigh-Ann as she takes on new challenges.

We're on the web!

Try This!

Children with autism learn appropriate behaviours most meaningfully through direct association. Often, this direct association is combined with a strategy of positive or negative reinforcement. School staff and parents may deal with physical aggression manifested by the student with an ASD. The key is to attempt to teach the student the consequences arising from a right or wrong action. In both settings one can try the following "Consequence Map" to address a target behaviour and create the consistency needed between home and school.



Coming Soon!

In collaboration with the Abe Gold Learning Centre, ATEDM (Autisme et troubles envahissants du développement Montréal), the English Montreal School Board, FQATED (Fédération québécoise de l'autisme et des autres troubles envahissants du développement), Giant Steps, Projet interordres des commissions scolaires francophones de l'île de Montréal and Collège Montmorency, the Lester B. Pearson School Board is proud to present the upcoming Michelle Garcia Winner conference: *Social Thinking: Exploring the Spectrum of Perspective Teaching with Social Thinking Vocabulary* **November 3rd 2011** at Collège Montmorency in Laval.

For more information and to register, please visit : www.goldlearningcentre.com



Read All About It!

One of the most controversial events in autism research is nearing its conclusion. The research conducted by Andrew Wakefield in 1998 that claimed a causal connection between the MMR (Mumps, Measles, Rubella) vaccine and autism has been discredited. As all subsequent attempts to replicate his findings were unsuccessful, an investigation was launched by the British Medical Council. This investigation revealed multiple problems with the original research including unfounded claims based on the inaccurate interpretation of his results, misrepresentation of who the participants in the study were, a failure to obtain adequate ethical approval from an institutional review board, and the exposure of child participants to invasive medical procedures such as colonoscopies and lumbar punctures. It was also discovered that Wakefield had applied for a patent on a single vaccine for measles before his campaign against the MMR vaccine began; indicating a personal business endeavor that might have benefited from the MMR Vaccine scare. According to Begley (2010), Wakefield's claims caused a precipitous decline in vaccinations that ultimately led to a number of children falling ill and several fatalities. In May of 2010, Dr. Wakefield was struck off the medical register in the United Kingdom and in the United States. It should be noted, that Andrew Wakefield continues to deny allegations against him and still has a following of supporters. Hopefully, this dramatic reconsideration of Wakefield's research puts an end to parental ambivalence about administering the MMR vaccine because of the fear that their child might develop autism.

For more information, please see the article in Time Magazine entitled, "Dr. in MMR/Autism Scare Ruled Unethical" (Friday, January 29th, 2010) or "Autism Study Yanked" (February 1st, 2010) in Newsweek.

References:

Sabrina Gabriele

Begley, S. (2010). Autism study yanked: but it's not likely to affect the anti-vaccine movement. Retrieved from <http://www.time.com/time/health/article/0,8599,1957656,00.html>

Deer, B. (2011). How the vaccine crisis was meant to make money/ BMJ 342: c5258. Retrieved March 10th, 2011 from <http://www.cnn.com/2011/HEALTH/01/11/autism.vaccines/?hpt=Sbin>. Retrieved 2011-01-12.

Godlee, F., Marcovitch, H., Smith, J. (2011). Wakefield's article linking MMR vaccine and autism was fraudulent. BMJ 343:c7452. Retrieved March 10th, 2011 from <http://www.bmj.com/content/342/bmj.c7452.full>. BMJ 2011; 342:c7452 doi: 10.1136/bmj.c7452

Harrell, E. (2010). Dr. in MMR/autism scare ruled unethical. Retrieved from <http://www.time.com/time/health/article/0,8599,1957656,00.html>

Wakefield AJ, Murch SH, Anthony A, Linnell, Casson DM, Malik M, et al. (1998). Ileal lymphoid nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children [retracted]. Lancet 351:637-41.