

The Autism

newslink



Autism Society Ontario
Fall 2004
VOLUME 1 • NUMBER 4

TOONIE FOR AUTISM DAY 2004

Annual Education Issue

Finding the Way Back Home

A visual tool

La bonne route a chez moi

Un outil visuel



The Autism
newslink The inside story...

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From our Executive Director...

The apparently gentle touch reflected in the image on the cover of this issue of The Autism Newslink captures only one aspect of the enormous bronze sculpture by artist Linda Brunker, recently photographed near a canal in Waterford, Ireland. What one cannot see of the artist’s work are the long bronze ribbons of the arms stretching out determinedly from either side in order to make that connection. Touch is one of those topics in autism that generates conversations about hopes, myths and moments of clarity about the experience of shared humanity, but which rarely permits indifference. Ask any parent or teacher of a child with autism about the experience of fleeting touch, hand over hand prompting, a painful pinch received or about trying to physically assist a child whose hands seem incapable of pulling on a shoe but who can hold onto a crumpled plastic straw as if his life depended on it. From the child’s perspective at that moment, perhaps it does. From the educator’s perspective, it lengthens the list of considerations for IEP goals.

So we try to understand, to negotiate—sometimes with words, other times with gestures or pictures—the nature or necessity of contact between two individuals in relationship to learning. There is the dad who knows that his son with autism cannot tolerate a firmly clasped hand, but allows a certain connection through the gentle linking of curled finger tips which direct the child in the way he might go. There are so many things to be worked on. This is good enough for now. There is the teacher whose student cannot go from one part of the school to another without holding firmly to her hand because he might bolt. They are slowly working on greater independence. The non-verbal student who firmly pulls a teacher’s forehead to press it to her own challenges the teacher’s understanding of touch and its relationship to communication in autism. And there is the student with Asperger’s who exceeds academically, wishes fervently to be included with peers but who finds it difficult to be in a room where unintentional touch from the people around him prompts him to push back in order to feel safe, because surprise touch produces tremendous anxiety for him.

Even when the connection for learning between us and children on the spectrum seems at times elusive, it is our hope that some of the tools in this issue will assist our readers to understand their own responses better as well as the responses of their students. Along the way, parents and educators do well to have regular and positive contacts in order to increase the likelihood that the students will be firmly supported in their learning.

Margaret Spoelstra, Executive Director



Putting a Face on the ASO Provincial Office

How many times do you make a phone call and talk to a faceless voice? Often, you think it would be nice to “know” to whom you were talking. Below are the main “family members” of the ASO provincial staff.

From Left to right: Ethel Berry (Manager, Information, Member and Donor Services), Margaret Spoelstra (Executive Director), Barbara Worrall (Administrative Staff), Bonnie McPhail (TOONIE FOR AUTISM DAY Co-Chair), Ron Harrison (TOONIE FOR AUTISM DAY Co-Chair), Esther Zhou (Bookkeeper), Jean Woolford (Special Projects), Yao Jie (Bookkeeping Assistant).

Although our family is constantly changing and growing, here are a few more you should know about. **Board of Directors:** Mehran Alaei, Nancy Ambrogio, Nancy Blake, Leslie Broun, Lynda Clayton, Christine Dade, Claudio Del Duca (President), Linda Gibson, Jane Houlden (Chair, President’s Council), Deborah Kitchen, Ginny Pearce, Monica Richardson, Jason Smith, Lonnie Zwaigenbaum. **Regional Support Leaders:** Lynda Beedham, Liz Cohen, Robin Frkovic, Jane McLaren, Anne Wittich. Others: Anna Donato (TOONIE FOR AUTISM DAY Manager), Patricia Gallin (ASO Program Support Coordinator) Bruce McIntosh (Consultant).

Attention
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We often reference web-sites or e-mail address in articles to obtain additional information. We recognize that not everyone has the ability to make connections through the internet. If you require additional information regarding a particular article or advertisement, please contact your local ASO chapter for assistance. ASO Newslink Editor

*I just wanted
to know
if there
are other
families like
mine...*

Anyone wishing to connect with the Bruno family by e-mail should contact ASO's provincial office at mail@autismsociety.on.ca

Send letters to the editor to mail@autismsociety.on.ca or write ASO, 1179A King St. W. Suite 004, Toronto, ON M6K 3C5

Trying to Relate

I am the parent of an 11-year-old son with severe autism. He is extremely challenged and our life revolves around him and his needs 100 percent of the time.

Although I enjoy reading *The Newslink* when it arrives, I have noticed that there aren't usually any articles that pertain to the lifestyle my family and I have because of our son's autism.

I would like to read about other families and how they cope with extreme challenges. Are there other parents out there who panic with each of their birthdays because they realize that they are again one year closer to becoming a senior citizen who will have to care for a toddler? Are there other folks like us who cannot have any respite because their child will not (no matter what strategies have been tried) tolerate a worker—whether it's male or female or even one of each at the same time? Are other people going out with their autistic children as a family only to have strangers stare, or rudely comment because the child is loud due to an uncontrollable vocal tic? Do other families have their furniture reinforced, doors with reverse locks, fences locked, and do 40 loads of laundry per week because of their child? Do they wonder why they have been dealt this hand only to have their autistic child then do something to make them laugh so hard that they decide it's really not so bad and they plug along again until the next time? Do other families give up

socializing with friends and families during holidays because it is too much for the child? Do the parents try all the different meds out there hoping for the magic panacea that will improve the quality of life for their child ...and then try to decipher if there are any side effects because the child is non-verbal? Do they exist on very little sleep because their autistic child just doesn't require the same amount of sleep as other people? These are the kinds of people I want to hear about.

This is just a glimpse of what life is like with our son Brody. We also have another son, Tyson, who is 9 years old and has Tuberous Sclerosis with A.D.D. (Attention Deficit Disorder) and O.D.D. (Oppositional Defiant Disorder).

I am always thrilled to hear of another success story about a person with ASD but I would also like to know about people like us that we can actually relate to. Even in our local chapter we don't have families like ours except for one and we are very close with that one family ...although due to the high anxiety levels of our children we are not able to socialize.

Anyway, I just wanted to know if there are other families like mine that you have heard from and if so please print some of their stories ...or print our story... it would make the connection between your message and the people you want to reach more complete. Thanks so much for listening.

Mimo, Yvonne, Brody and Tyson Bruno

When Someone "Gets" It

Rowan's great day came down to the ingenuity of a phenomenal and determined Educational Assistant (EA). Always a bit of a "bolter" and/or "wanderer," Rowan has always had to hold hands when moving from place to place. His phenomenal and determined Educational Assistant (EA) has been working hard on independent walking at school. Each day after school I take him to shops, pharmacies, etc., —just a quick trip to pick up one or two items—to help generalize the skill. For a few weeks he'd been doing a fantastic job and while I thought "mission accomplished," his ingenious EA had bigger and better plans. To be honest, I was terrified when she told me, but I nervously and excitedly thought, "He can do that!"

One morning she brought her walkie-talkies to school, gave one to the librarian and kept one in the classroom. She then radioed the librarian to let her know Rowan was on his

way *by himself*. When he arrived, the librarian let his EA know he'd made it there. They read a book together and she sent him back to class.

I happened to be on lunchroom hot dog duty that day so she brought me a walkie-talkie and then sent him down to "see Mom." I peeked around the corner to see him walking up the empty hallway all on his own—head up, hands down at his sides—he had never looked so grown up or so gorgeous!

To top it off he got back his perfect spelling test (the sixth in a row!), and when we went to the pharmacy after school he said, "Hi Angie!" to the pharmacist assistant—*his first spontaneous greeting ever in his whole life!* An all-round great day! This definitely makes up for the fact that he coated the living-room window in black shoe polish the day before.

Michelle Murdoch-Gibson

Executive Functions and the Brain

by Valorie Salimpoor

The frontal lobes of the brain are home to a complex group of mental processes known as executive functions that are responsible for our ability to plan ahead and organize our behaviour in order to accomplish future goals. We use these skills every day when we think about what we have to do, organize our thoughts, control impulses, come up with ideas, solve problems and integrate feedback from our environment. Deficits in executive functioning can negatively affect many aspects of our daily lives. In children, difficulty with these functions can severely impact social, cognitive, emotional and behavioural development and interfere with learning and academic achievement. These underrated mental processes are common to numerous developmental disabilities such as Autism Spectrum Disorder (ASD), Attention Deficit/Hyperactivity Disorder and learning disabilities.

Children with executive function deficits often show difficulty with planning ahead and organizing their thoughts or behaviour. They also show poor reasoning and judgment, have trouble coming up with and applying strategies, find it difficult to imagine abstract or multiple solutions to a problem, get stuck on one way of solving a problem, can be impulsive, have a hard time controlling their emotions and have difficulty monitoring or regulating their behaviour. At school, difficulty with any of these skills can pose a serious impediment to learning and academic achievement. No matter how good a student's knowledge might be in a particular subject, their performance can be negatively affected if they have trouble with executive skills. For example, in the classroom, students who are not able to concentrate, inhibit distractions and focus attention will have trouble following the teacher and processing information. While solving a math problem, children may know

their facts well, but still not be able to come up with a solution if they have difficulty organizing their ideas, have trouble coming up with a strategy, and find it difficult to mentally integrate information to solve the problem. Some children may be unable to come up with solutions spontaneously or may get stuck on one method of solving a problem. Children with executive deficits also tend to show socially inappropriate behaviour and poor interpersonal skills. It is not surprising that problems with various aspects of adaptive behaviour such as communication, play and social relationships have been associated with executive dysfunction (Gilotty, Kenworthy, Sirian, Black, & Wagner, 2002). In summary, difficulties with executive function extend to the home and other environments, affecting not only academic but everyday functioning as well. Moreover, due to the covert nature of executive impairments, they are often missed or overlooked, or mistaken for lack of motivation, laziness or impulsivity.

Although there have been studies to look at executive dysfunction and autism, few studies have formally tested executive skills in children with Asperger's Syndrome (AS). Numerous symptoms of executive function deficits are reminiscent of the typical features of AS such as the need for sameness, lack of planning, impulsivity and circumscribed interests. Since executive function is important for and related to virtually all other domains of cognition—learning, memory, higher-order information processing, manipulating information, organizing behaviour, language and visual processing—their impact on learning and academic functioning can have severe consequences for those affected. Thus it is important to recognize these deficits early and apply appropriate training.

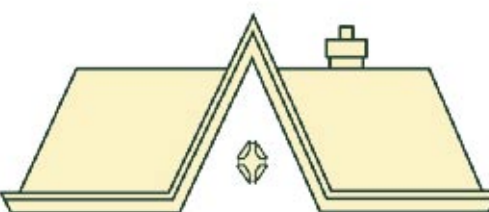


Valorie Salimpoor is a research student at York University, Toronto.

References: Gilotty, L., Kenworthy, L., Sirian, L., Black, D. O., & Wagner, A. E. (2002). Adaptive skills and executive function in autism spectrum disorders. *Child Neuropsychology. Special Issue: Behavior Rating Inventory of Executive Function (BRIEF)*, 8(4), 241-248.



ASO would like to acknowledge Jeff Dobbin of Parashoot Productions for his efforts in producing our videos: *Meet My Brother*, *A Chance to Be Me* and *In Our Own Words*. All three videos have been well received and many of our chapters have found them to be very beneficial. We encourage organizations interested in producing video, DVD or multimedia projects to contact Jeff at jdobbin@parashoot.ca or visit his site at www.parashoot.ca.



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We are currently recruiting children between the ages of 6 to 18 who have been diagnosed with Asperger's Syndrome. If you are interested in participating, or want to find out more about the results of our study please contact Valorie Salimpoor at valorie@yorku.ca. Participation in this study takes about two hours and participants are compensated for their time.

by Sheila Bell, Speech and Language Pathologist



Once executive dysfunctions have been identified, intervention programs can be designed that specifically target each aspect of the executive deficits. For example, children may be taught problem solving strategies, metacognitive skills, use of mnemonic devices, study skills, self-regulation training, visual imagery for memory enhancement, task-specific routines, self-talk and self-monitoring and other methods for compensation. To help compensate for executive deficits, external supports may be used such as master calendars, cues, prompts, picture-assists, checklists, to-do lists, written instructions and signs. Furthermore, external devices can be used such as electronic organizers, alarms, tape recorders, watches and timers to assist with organization, planning and time management. Children's environment can also be used to supply external structure to facilitate these skills. For example, modifications can be made in the classroom to incorporate well-planned activities and eliminate distractions. Additionally, teachers and parents should make every attempt to apply consistent routines and rules, present instructions clearly, and explicitly identify assignment goals and sub-goals. Such modifications in the child's home and school environment can facilitate more independent executive functioning.

Teaching Students with ASD

Dealing with Stress and Anxiety

Individuals with Autism and Asperger's Syndrome (AS) experience stress and anxiety on a daily basis. This high stress/anxiety level usually becomes obvious as loud and difficult behaviour. Your challenge as a teacher is to read the small signs of "anxiety rising," before you reach the stage of loud disruptive behaviour that will disorganize your entire classroom.

Here are some of the common sources of stress/anxiety for ASD individuals:

- **Weak language skills** (inability to follow verbal interactions "at speed;" misunderstanding of what someone has said; inability to quickly and clearly express needs and wants).
- **Weak social interaction skills** (inability to follow a social interaction "at speed;" inability to read subtle social cues such as tone of voice and facial expression; misunderstanding of motivation of another person; negative association with previous "social interactions gone wrong").
- **Academic work which is above the student's level** (may be able to do the "form" but not understand the "content;" may not understand the language of instruction; may be

The first step to remediation of executive dysfunction is accurate assessment. The purpose of our study taking place at York University in collaboration with Dr. Mary Desrocher and Dr. James Bebko, is to look at how executive dysfunction affects children with AS. Once the specific executive impairments have been identified, appropriate intervention can be applied to improve learning skills and academic performance. Such difficulties can be compensated for by carefully structured educational and remediation programs. It is important for structured educational programs to begin early in life in order to increase learning opportunities and minimize problems in learning due to difficulty with executive skills. Providing specific intervention programs that target executive dysfunction is feasible and can significantly decrease problems in virtually all subjects at school.

This project was made possible by the generous contributions made to Autism Society Ontario's *TOONIE FOR AUTISM DAY* campaign. These funds have helped us learn more about cognitive functions and how they relate to academic performance in children with Asperger's Syndrome.

overwhelmed by the total amount of work or the speed of presentation of new material)

- **Homework** (see Tony Attwood's article, *Should children with an Autistic Spectrum Disorder be exempted from doing homework?* available on his website at www.tonyattwood.com under "Papers").
- **Measurement of performance** (eg. making mistakes; winning and losing; being first in line; being ranked in class). This can cause stress even if the child is first because they fear falling from that position. For these individuals, perfection and winning seem to represent "safety." They do not strive for the top for the same reasons as other high achievers.
- **Change in routine or schedule** (especially if the change is not anticipated and is explained verbally).
- **Sensory overload** (may be hypersensitive to noise, light, touch, smell).
- **"Missing things"** This seems to be a focus of anxiety for some individuals with ASD (maybe because these individuals frequently "miss" pieces of information in the course of everyday events and expend a lot of "thinking energy" trying to fill in the gaps in their

knowledge; to miss an entire event may seem like too much to catch up on).

- **Seasonal disintegration** Some individuals with AS experience higher anxiety at certain seasons of the year. This may correspond to seasonal allergies (some have conventional allergy symptoms such as headaches, congestion, asthma and itchy eyes, as well as displaying frustration, inattention, emotional lability and other difficult behaviours).

What are the "small signs" of stress rising?

These will vary depending on the student. It is important to identify these subtle behaviour changes in your ASD student in order to intervene before more spectacular negative behaviours occur. Here are some behaviours you might see:

- **Small "tics" and repetitive behaviours** (eg. eye blinks, facial grimaces, nose or throat noises, head movements, arm or hand movements)
- **Language scripting** (eg. reciting language from a movie or book, apparently unrelated to the situation) - certain phrases may reliably indicate stress (eg. "Do I *have* to do it?")
- **Distressed or angry facial expression**
- **Whole body movement** (eg. getting up from desk and pacing, rocking, throwing things)
- **Inappropriate laughter**
- **Rising volume and/or tone of voice**

What can I do to reduce stress and anxiety in the classroom?

1. Identify the sources of stress

- Look at the context of the behaviour (what happened just before, at the same time, just after).
- Make a "best guess" about the source, then make changes based on that guess (eg. if the level of the work is too hard, try modifying the academic materials; if the noise level in the classroom is too high, try to create a quiet working space for the student).
- If signs of stress lessen with the changes you make, you're on the right track; if stress level remains the same or rises, you need to look at the situation again, and see what else might be causing the student's distress.

2. Structure and routine in the classroom

- Many teaching approaches advocated for ASD students take advantage of the calming effect of structure, routine and predictability (eg. TEACCH).
- Typically developing students constantly take in auditory and visual information that helps them predict, with a fair degree of certainty, what will happen next; they depend on their language skills to help them figure out what's happening if suddenly the situation is unfolding in an unpredictable way. ASD students do not take in this information and life is often a series of unpleasant surprises. The more you can remove the element of surprise from the

classroom situation, the calmer your student will be.

- Establish a routine early in the school year; write it out in social story format; use visual cues from the story (eg. reminder cards) to help the student connect the real-life situation to the one described in the story.

3. Use visual supports to back-up verbal language

- It's a good rule of thumb to back up all verbal information with written (and/or picture) support.
- Individual written/picture information sheets at the student's desk are optimal (even if you have a large visual for the entire class).
- Visual supports can decrease the general anxiety about missing information.

4. Visual/written schedules

- Students with AS should work from a visual/written schedule.
- Large schedules can include all of the day's events; need to be readily available for checking throughout the day (may be posted in the classroom, or at the student's desk).
- Anxiety over transitions and changes in schedule are reduced when the schedule is written down (student comes to count on the information being correct and the "last word" on what is happening).
- Smaller "task schedules" can help students to manage academic work independently; they can see how much there is to be done, and when their breaks will be.
- It may be useful to teach the student how to read a digital clock and connect their personal schedules to observable time displays (ASD individuals tend to have a poor inner sense of the passage of time).

5. Modified academic work

- Focus on the language level of the academic tasks. This is frequently the stress-inducing piece (eg. student may be strong in math, but may not understand the language used to describe new concepts).
- Instructions should use simple language structures and vocabulary.
- Make use of visual instructions and demonstration.
- Support student's learning of new vocabulary (have appropriate level dictionary available at workplace, demonstrate how to use the dictionary, perhaps begin a personal dictionary of new words learned in the context of school topics).
- Intersperse "language-intense" tasks with activities that are more visual, to allow "thinking breaks."

6. Use of favourite topics

- You can get an anxious child to approach new concepts by presenting them in the context of favourite topics. Use your imagination (eg., if a child likes maps, and your math topic is mea-

“It is important to identify these subtle behaviour changes in your ASD student in order to intervene before more spectacular negative behaviours occur”

The student with ASD should have identified “safety people” within the school, available at all times during the school day (adults, not peers). These “safety people” are known to have the answers to difficult social questions and are able to help the ASD student find workable solutions to everyday problems. All identified helpers should have a working understanding of this particular student’s difficulties.

- asuring linear distance, get the child to measure different driving routes through the city and compare to see which is longer).
- Figure out the key objective of an academic activity, then brainstorm with other school personnel about how to achieve that goal using unconventional means (eg. “1-1 counting,” rather than “use a number line”).
 - For a child who loves gross motor play, add counting and letter/word skills into play with a small trampoline, physio ball or other items from your sensory room.

7. Homework

- The ASD student expends a lot of energy just keeping up with the requirements of the regular classroom activities. If he also has to do several hours of homework at night, he will constantly be running at a very high stress level. If the ASD student consistently cannot finish the regular classroom workload, decrease the overall amount of work and modify the way of presenting the concepts, so that individual tasks are not as taxing.
- To encourage the pattern of academic activities outside of the school environment, consider allowing the child to do special interest projects at their own speed that can then be presented by the child to his/her classmates. Many ASD students already have extra therapy and tutoring sessions outside of school hours; their schedules are often formidable.

8. Direct teaching of social skills

- This is done effectively through social stories, social problem solving and role-playing.
- As teachers, you have the best opportunity

- to observe the student’s classroom and play-ground interactions with peers and to identify problems.
- Pass this information on to those who work 1-1 with the student (resource teachers, educational assistants, tutors, parents or outside professionals), so that direct teaching of more positive social responses can occur.
 - Once social skills have been presented in a 1-1 setting, teachers and EAs in the classroom can support the student in using new skills in everyday situations.

9. Body breaks

- Intersperse sit-down thinking activities with chances to get up and move around (some schools have special rooms set up for students to take a fun “body break”). Physical movement can help ASD students release tension, clear their heads and be ready to sit down and concentrate.

10. Seasonally modified requirements

- Some individuals on the autism spectrum have extreme reactions to seasonal changes. You may notice increased stress/anxiety and irritability, increased emotional lability (quick laughter, tears and anger), and an increase in difficult and disruptive behaviour. You may need to modify classroom requirements to handle the child’s changed physical state. You might want to decrease the amount (and level) of spoken language that must be processed, allow more frequent “body breaks,” work more through highly favourite topics, maintain academic activities rather than introducing new topics.

your arms off the ground as high as you can. Now try to talk. Imagine how hard it would be to breathe if considerable force was placed on your back.” The prone position restricts the muscles that control the lungs and in an extreme situation places considerable stress on the heart’s ability to function.

The coroners’ inquests into the deaths of both Stephanie Jobin and William Edgar advise against the use of prone restraints. The Crisis Prevention Institute, the providers of the training program Non-Violent Crisis Intervention, used by school boards throughout the province, also warns against the use of prone restraints, agreeing that they interfere with one’s ability to breathe. Yet there is at present no consistent provincial prohibition against such dangerous practices in schools. Steve Darby warns that unsafe methods are still used. “My travels teaching crisis prevention throughout the province have taught me that Ontario schools are a patchwork of good and bad practices.” Though the vast majority of programs employ the most up-to-date crisis prevention/management methods, he admits that he frequently confronts unsafe situations. “Children are in grave danger when such strategies are used.”

A further concern is the use of what can best be termed improvised mechanical restraints in classrooms. An improvised mechanical restraint could range from the use of a belt to prevent a child from exiting from a chair, to the misuse of Velcro straps on wheelchairs originally designed to help children with physical disabilities such as cerebral palsy. The motives for using such devices are often positive. Staff might employ a mechanical restraint, for instance, to prevent a child from striking themselves in frustration or from leaving a classroom. Whatever the motive however, such improvised devices are not supported by any approved crisis management course and are dangerous. A major factor in Stephanie Jobin’s death, for example, was the use of a beanbag chair as a restraint tool.

Prevention is the Key

The best way to keep everyone safe is to understand that no form of physical restraint is completely “safe.” Dr. Ann McGlone-Rankin, Special Education Department Head at St. Mary’s Catholic Secondary School in Hamilton stresses what she believes is essential to limit the use of restraint. “We know that all restraint, even when necessary, is risky. Confronted by a difficult situation we always ask ourselves the question, “Is this situation so serious that I am willing to risk the safety of a student by attempting to use restraint?” Almost always, the answer is no.” Dr. McGlone adds that by modifying elements in a student’s environment, her staff is almost always able to avoid the need for restraint altogether. In the unfortunate event that some form of physical

intervention is required, it is also essential that staff be adequately trained in approved crisis prevention and management methods that maximize safety and focus on least intrusive methods.

Dave Sadonoja, an educational assistant and manager of a high-need autism summer respite program adds, “When we work with a child with challenging behaviours we ask ourselves, ‘what would we have to modify in this student’s day to avoid physical crisis?’ Then, whatever it is, we do it.” He stresses that the ever-present dangers associated with crisis behaviour and restraint demand that staff be very flexible with programming. “To the extent that the crisis behaviour is an issue, absolutely no part of the child’s environment is exempt from change.”

The death of children with special needs like Stephanie is a tragedy. However, by using her unfortunate death as a call to educate everyone on the dangers of restraint, we can reduce the possibility that there will be future restraint-related tragedies.

Ed Mabony is a Special Education Resource Teacher for the Hamilton District Catholic School Board and an associate instructor at Conestoga College. He presents to groups regarding restraint issues throughout the province. He can be reached at edmahony@alumni.uwaterloo.ca

Steve Darby is a crisis prevention consultant and Teaches “Retbinking Restraint” a crisis prevention program focusing on individuals and other special needs. He can be reached at stevedarby@exceptional-needs.ca

“What would we have to modify ...to avoid physical crisis?”

Exercising Restraint

HER BEHAVIOUR WORSENERD. TWO CARE WORKERS FORCED HER ON HER STOMACH AND PLACED A BEAN BAG ON HER BACK. ONE KNELT ON HER SHOULDER BLADES, THE OTHER HELD DOWN HER LEGS. AFTER 20 MINUTES OF BEING RESTRAINED STEPHANIE SUDDENLY WENT MOTIONLESS AND STOPPED BREATHING. STEPHANIE WAS RUSHED TO SICK CHILDREN’S HOSPITAL IN TORONTO. THREE DAYS LATER SHE DIED.

W-5 segment “Restraining Stephanie” CTV, Friday, February 22, 2002

Physical Restraint is a little spoken of yet all too serious reality in Ontario schools. Often euphemistically called Physical Intervention, restraint is the use of force to limit an individual’s movement. It is permitted in virtually every educational jurisdiction as a means to protect an acting-out student and those around him when they pose a direct and immediate serious threat. Unfortunately, the

use of outdated and dangerous restraints can result in injury and even death.

In 1998 a 13-year-old, Stephanie Jobin, died as a result of being restrained in a Toronto area group home. In 2001, 13-year-old William Edgar also died as a result of being held on the floor on his stomach by group home staff. Both children had special needs. In fact, the vast majority of physical restraint used in schools involves students with such special needs as autism, Tourette Syndrome or other disorders. The circumstances surrounding the deaths of these two children can teach us life-saving lessons.

Prone Restraints

Prone, or floor restraints place an individual on their chest on the floor and hold them by applying pressure in some way. They are cited by experts as dangerous. Steve Darby, a special needs crisis prevention consultant, explains that placing force on a person’s chest hinders breathing. “Try lying on your stomach and lift

by Ed Mabony, Special Education Resource Teacher



DA NGEROUS RESTRAINT PRACTICES

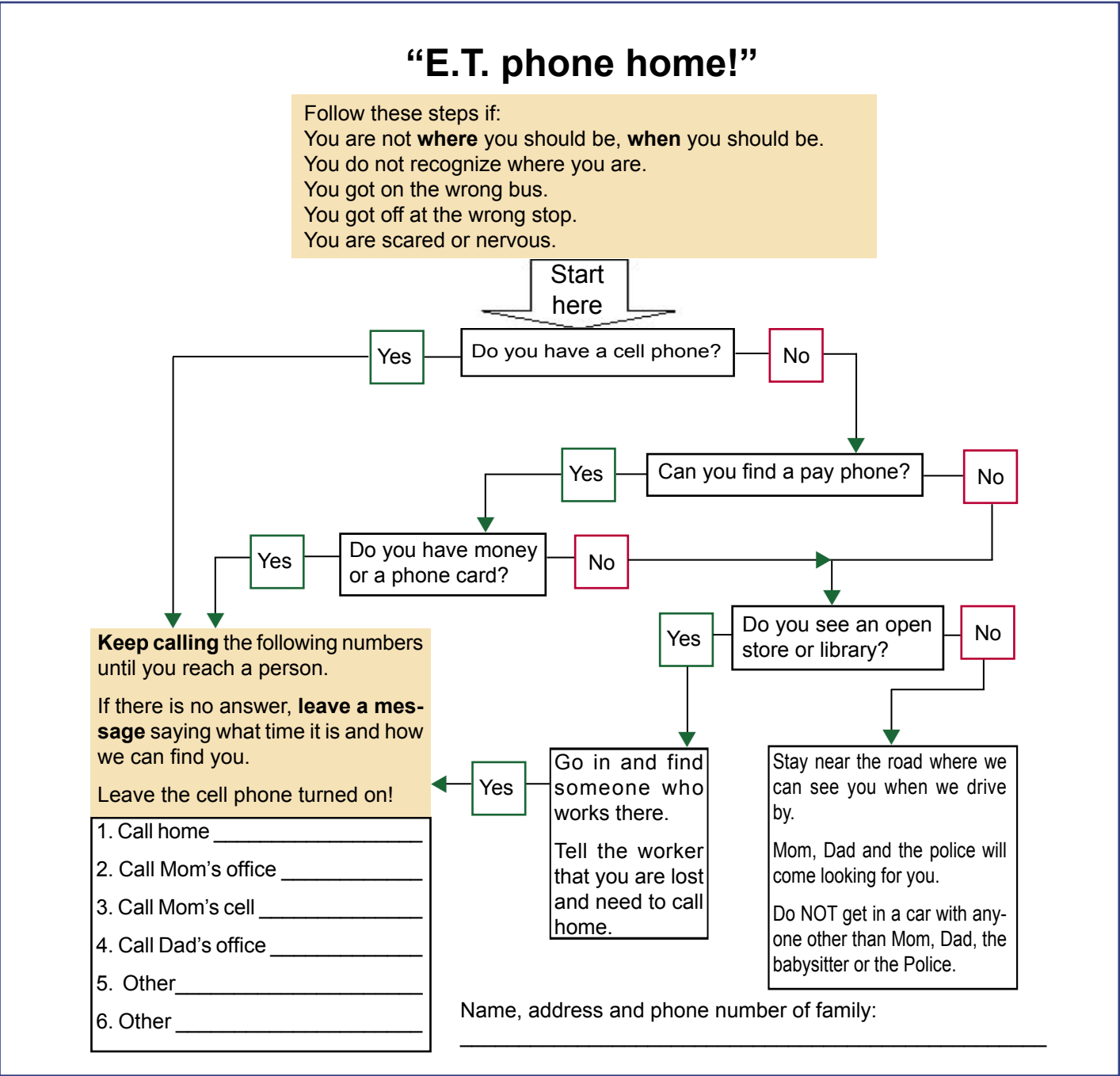
- Do not hold a student on the floor or place pressure in any way that restricts their ability to breathe.
- Do not improvise mechanical restraints.

WAYS TO AVOID RESTRAINT

- Become trained in approved Crisis Prevention Courses.
- Imagine what you would have to do to have a crisis-free day and do it.
- Make everyone aware of the dangers of restraint.
- Celebrate crisis-free times.
- Learn about ways to modify environments.
- Remember that to the extent that crisis behaviour is an issue, every aspect of a student’s day must be open to change.

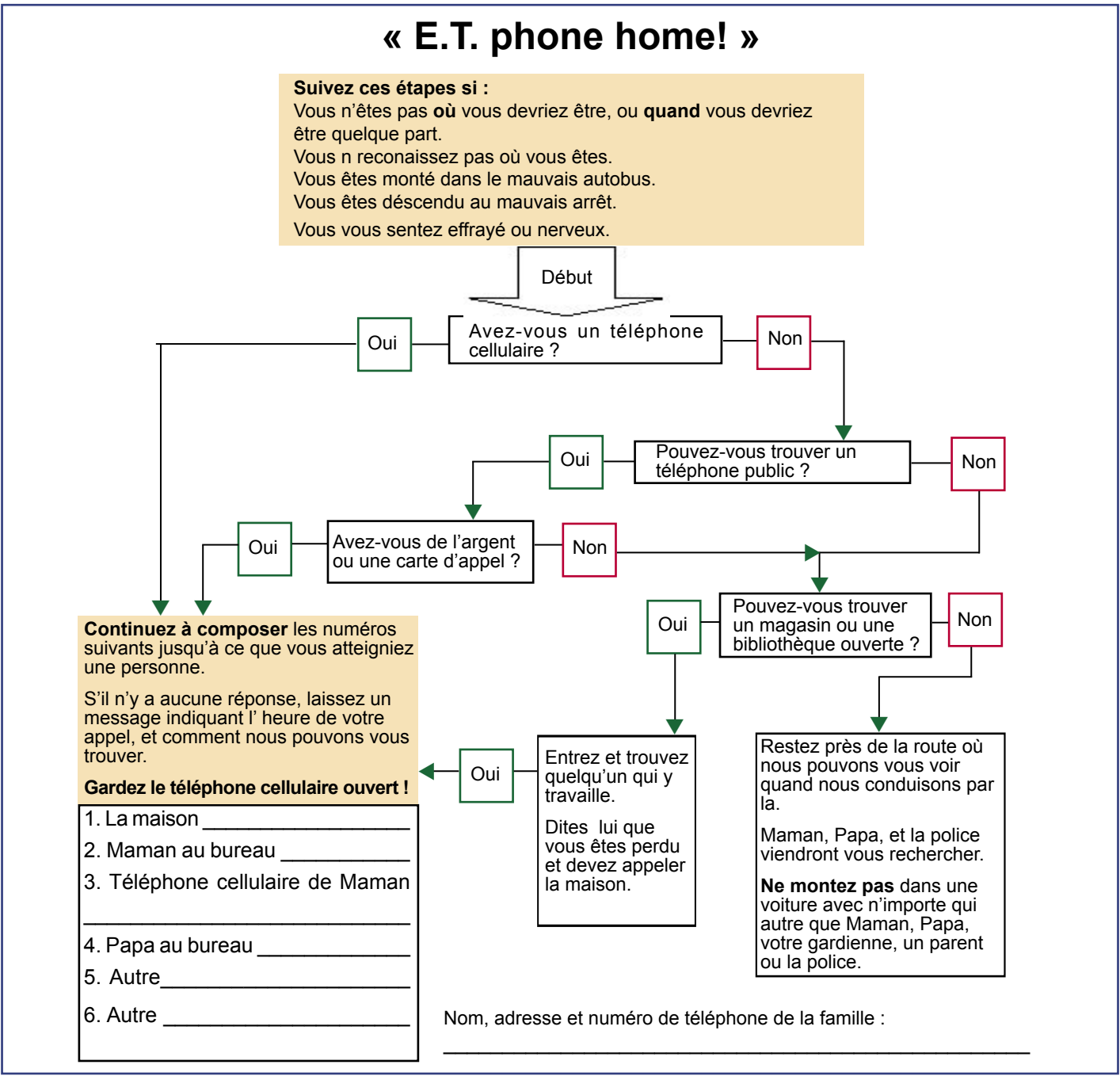
Finding the way back home

Steve and Wynn Anne Sibbald of Ottawa have created this visual tool which could be adapted to help any child to cope with getting lost. “We’ve had so many close calls with our son Peter (getting lost and not knowing what to do next), that we finally made up a flow chart for him,” says Wynn Anne. “As a supremely logical fellow, he really appreciated the linearity and logic of it. Our 11-year-old daughter also appreciated the chart, and made suggestions to improve it. It’s easy to visualize lots of applications for a flowchart like this.”



La bonne route a chez moi

Steve et Wynn Sibbald d’Ottawa ont créé cet outil visuel qui pourrait être adapté pour aider n’importe quel enfant à faire face à se trouver perdu. « Nous avons eu plusieurs crises avec notre fils Peter (lorsqu’il s’était perdu et ne savait pas ce qu’il devrait faire), que nous avons finalement composé un organigramme pour lui, » dit Wynn Anne. « En tant qu’il est très logique, il a vraiment apprécié les linéarités et la logique qui s’y trouve. Notre fille âgée de 11 ans l’a apprécié aussi, et a suggéré des améliorations. Il est facile de visualiser un bon nombre d’usages pour un tel organigramme. »



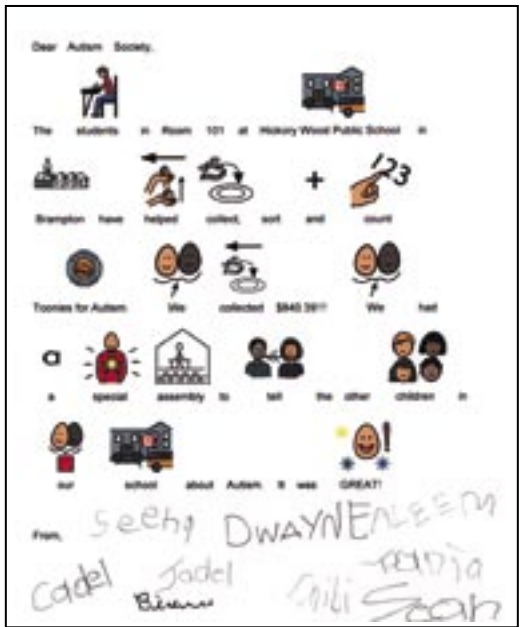
Material on these pages collected and provided by TOONIE FOR AUTISM DAY co-chairs Ron Harrison and Bonnie McPhail



Central Park P.S., Dundas



Edna Thompson Childcare, Bowmanville



Hickory Wood P.S., Brampton

A wide variety of participants again accepted our 3rd annual *TOONIE FOR AUTISM DAY* campaign challenge. This speaks highly of the dedication of educators and parents who realize the value of this endeavour.

This year's campaign involved 71 school boards and over 503 public and separate schools, including 32 French schools. Private schools, nursery schools and daycare facilities also came on board as well as three universities and colleges, 27 health care facilities, 44 corporations, organizations and clubs, plus many personal donations. The committee received overwhelming feedback on our new video *A Chance to Be Me* which is geared towards older students (grades 6 and up), as well as *Meet My Brother* from our previous campaign. Thanks go out to Jeff Dobbin and Parashoot Productions for another outstanding view of life within the autism spectrum!

The 2004 campaign attracted more than 121 new participants. Besides the new level of awareness of autism, to date more than \$225,000 has been raised for autism research. More than 365,600 students and staff and over 1,279,600 families across Ontario participated. At the time of publication, more than 94 registered participants have not yet submitted funds.

We would like to express our sincere thanks to all who assisted with this year's *TOONIE FOR AUTISM DAY* campaign. Without your help this campaign would not be as successful as it is.

Next year's official *TOONIE FOR AUTISM DAY* is set for **Friday, April 29, 2005**. Please note that another day may be more appropriate for some schools and we will do our utmost to accommodate. Just insert the date of 'your event' upon registering. We look forward to working together once again to raise autism awareness throughout Ontario.

Grade 4 students at **ADAMSDALE P.S. in Sudbury** shared information they learned about autism from your website, during morning announcements. Their words helped to create awareness and understanding of autism and empathy for all students with special needs and differences.

As the ASD teacher at **BAYVIEW ELEMENTARY SCHOOL in Midland**, I feel very proud of our staff and student body. The support and friendship that is demonstrated towards our students on a daily basis is something to celebrate. The movie and the literature helped our school-wide understanding of autism.

It was really neat to be a part of such exciting events that helped raise funds and awareness, as well as providing our staff and students with the opportunity to work and have fun together. **BEAVER BRAE SECONDARY SCHOOL in Kenora**

We have a special place in our hearts for your organization and I hope that our donation will contribute to continued research in autism. **BOXWOOD P.S. in Markham**

BRIARDALE P.S. in St. Catharines kicked off our *TOONIE FOR AUTISM* month in April by showing the videos *Meet My Brother* and *A Chance to Be Me*. There were a lot of good questions from the students. An autism information wall in the hall gave a brief overview of autism and some of the difficulties people with autism face. The students now understand a little more about why their friends do what they do and how they can help them.

A grade one student and his Educational Assistant traveled to each class and promoted classroom discussions and presented the video *Meet My Brother*. Staff and students learned why this type of learning environment is important for students with autism and other special needs. **BRECHIN P.S. in Brechin**

We understand first hand the need for research and greater support for individuals with autism. **CARDINAL CARTER CATHOLIC SECONDARY SCHOOL in Leamington**



Mrs. Coulson's class, St. Timothy's P.S.



Last year **CHERRYTREE P.S. in Brampton** raised just over \$400, so you can imagine how happy we were to almost double that amount this year. We realize the fundraising is important, but so is the increased awareness of autism within our school community.

Co-workers from other programs at the **NISSING-PARRY SOUND CHILDREN'S AID SOCIETY** were invited for "free" pizza and pop and to view the video *Meet My Brother*. It was our first time sponsoring *TOONIE FOR AUTISM DAY* and we will do it again next year.

GRANDVIEW P.S. in Bethany celebrated *TOONIE FOR AUTISM DAY* by creating an introduction sheet using *Writing with Symbols* and attached it to the information package created by ASO. The students were fascinated with the symbol page and were able to read the notice.

Comme activité, les élèves de la classe TED ont invité toute la communauté scolaire, élèves, membres du personnel et parents, à se joindre à eux pour leurs exercices journaliers. Tous au gymnase, se touchaient donc les orteils, tournaient à la taille, sautaient et couraient sur place. Les élèves de la classe TED ont passée dans toutes les classes de l'école afin de distribuer des muffins qu'ils avaient cuisinés. Se fût une excellente journée. **ÉCOLE CARREFOUR JEUNESSE en Rockland**

I am a Special Education and Resource Teacher as well as a parent of a child with ASD. My message was one of support and understanding for those who are differently abled, as well as one of courage and strength to meet the challenges we face in life. It ties in very well with our board's initiative on Character Education. **CROSSLANDS P.S. in Newmarket**

At **ENGLEHART P.S.** the students coloured a puzzle piece which was organized into a large display for Education Week titled, "We're helping to solve the puzzle that is autism." As a teacher and a parent of a child with autism, I commend you for all that you are doing. Keep up the great work.

All senior classes at **FOCUS ON FIVE MILE in Thunder Bay** viewed the video *A Chance to Be Me*. Some

classmates of our autistic student were starting to get tired of some of his habits and this movie just reinforced how "special" he really is!

HALIBURTON HIGHLANDS SECONDARY SCHOOL ran various fundraising activities "staffed" by our students with autism, which was a positive experience for them, and an awareness-raising forum for the student body.

At **HAZEL McCALLION P.S. in Mississauga** grade level assemblies discussed what autism is and showed the video you provided. We allowed students to ask questions about my contained class of autistic students. This resulted in a tremendous response with many students asking to volunteer in our classroom.

With four students with autism, this cause has a special meaning to us at **JOHN XXII in Arnprior**. *TOONIE FOR AUTISM DAY* brought a new awareness to our students and staff. The video *A Chance to Be Me* was helpful in making awareness of autism a reality.

Les enfants de de l'école **Cadiieux en Vanier** ont collaboré à produire une grande murale, un casse-tête de plus de 2 mètres de large et ont fabriqué en classe cinq casse-tête différents. En ce 30 avril, nous avons organisé un Gala hommage aux élèves de la classe TED et plusieurs parents se sont déplacés pour y assister. Situés dans un milieu défavorisé et concernés par cette problématique, nous sommes reconnaissants de cette participation massive.

Thank you for your continued excellent work and advocacy on behalf of individuals with autism and their families, both at the local Peel level as well as at the provincial level. **KERRY'S PLACE AUTISM SERVICES**

Our organization devoted the week to creating a better understanding of the work we undertake on behalf of children with autism through the Preschool Autism Services in Waterloo, Wellington and Dufferin. *Meet My Brother* gave great insights into the world of a child with autism and interplay within families who have a child with autism. The narrator was

For many individuals with autism, a picture is really worth a thousand words. If you are still learning about autism, wondering what this means, picture this. The Pope John Paul II (Bolton) education resource workers started a fundraising campaign that has grown from \$454 in 2000 to \$15,000 in 2004. The secret to their success: dedication, teamwork, love for the students with autism. This extraordinary team inspired the staff and student population to participate in oning education and fundraising. Classmates were learning first hand about autism. Fundraising incentives such as Pancake Tuesday, pot luck staff lunches, sale of cookbooks and barbeque lunches created an empowering commitment to integrating and enhancing the lives of those with autism.



École Catholique Le-Petit-Prince, Maple



Charlton-Savard P.S.



wonderful, precocious and quite charming and very effective in putting forward the message. Congratulations and keep up the good (and hard) work on behalf of the many children with autism. **KIDSABILITY – CENTRE FOR CHILD DEVELOPMENT**

The students at **MARY IMMACULATE COMMUNITY SCHOOL in Chepstow** are accustomed to this disorder as we have a child with autism enrolled in our school. He is a very unique young man and we are proud of the accomplishments that he has made with his E.A.

TOONIE FOR AUTISM DAY was great! All of the classes at **QUEENSVILLE P.S. in Queensville** came into our class to play and visit our new sensory integration room. I also went into all the other classrooms and showed videos and read the book *Amazingly Alpbie*. It has been a wonderful week!

QUINTE DAY TREATMENT in Belleville has a small group of students with big hearts

and great friends who have been diagnosed with ASD. This private school of 21 students dedicated many hours of preparation time towards fundraising for this event. Thank you for the opportunity for our students to surpass their own expectations of giving!

Our motto is: Living, Learning and Laughing. We are glad we were able to help you, which in turn will help all of us make a difference in the lives of children with autism.

RIVERVIEW P.S. in Cumberland

The Jr. Kindergarten student with autism that I work with as an E.A. at **SHEPPARD P.S. in Kitchener** had not been “Special Me” during the year, so this opportunity spread the day over a week-long period. A chart filled out by his parent helped his classmates get to know him much better. We highlighted his great strengths and uniqueness; and demonstrated the many similarities between all children. We received comments and several thank yous for

increasing awareness on the matter. It gives me such pleasure to see what great gains are made with such little effort.

To prepare for *TOONIE FOR AUTISM DAY*, we went to each class explaining autism and showing the videos. Hands-on experiments helped students realize what it would be like to be autistic. We touched them with sand paper, looked through baby food jars and had them write with really small pencils while wearing oven mitts. Some students wondered why the unfinished puzzle wall in our front hall has no edge. I told them that until there is a cure there would be no edge. **ST. ANDREW’S CATHOLIC SCHOOL in St. Andrew’s West**



Parent volunteers, St. Timothy’s P.S.

Is your school board in this list?

The 2004 Toonie for Autism Day campaign had a total of 71 boards with schools participating (out of approximately 100 school boards and school authorities in Ontario.) Participating boards are listed below, with the number of schools represented in parenthesis beside each name.

Algoma District (4)
Algonquin & Lakeshore Catholic (3)
Asquith-Garvey District Authority (1)
Avon Maitland District (4)
Bluewater District (5)
Brant-Haldimand Norfolk Catholic (1)
Bruce Grey Catholic (2)
Catholic D.S.B. of Eastern Ontario (6)
CSD Centre Sud-Ouest (6)
CSD Grand Nord de l’Ontario (1)
CSDC Franco-Nord (9)
CSDC Centre Est de l’Ontario (5)
CSD L’Est de l’Ontario (2)
CSD Nord-Est de l’Ontario (1)
CSDC Centre-Sud (3)
CSDC des Grandes Rivières (3)
CSD Sud-Ouest (1)
CSDC Nouvel-Ontario (1)
District School Board of Niagara (3)
District School Board of Ontario North East (4)
Dufferin-Peel Catholic (11)
Durham Catholic (10)
Durham District (37)
Grand Erie District (6)
Greater Essex County District (5)
Halton Catholic (4)
Halton District (4)
Hamilton Wentworth Catholic (4)
Hamilton Wentworth District (7)
Hastings Prince Edward District (6)
Huron Perth Catholic (2)
Huron Superior Catholic (2)
Kawartha Pineridge District (6)
Keewatin-Patricia District (14)
Kenora Catholic (1)
Lakehead District (13)

Lambton Kent District (2)
Limestone District (8)
London District Catholic (5)
Mine Centre DSAB (1)
Near North District (7)
Niagara Catholic (4)
Nipissing Parry Sound Catholic (3)
Northwest Catholic (1)
Northeastern Catholic (2)
Ottawa Carleton Catholic (13)
Ottawa Carleton District (11)
Peel District (28)
Peterborough Victoria Northumberland Catholic (14)
Rainbow District (3)
Rainy River District (1)
Red Lake Area & Combined (1)
Renfrew County Catholic (4)
Renfrew County District (4)
Simcoe County District (7)
Simcoe Muskoka Catholic (16)
St. Clair Catholic (3)
Superior-Greenstone District (1)
Superior North Catholic (2)
Thames Valley District (20)
Thunder Bay Catholic (4)
Toronto Catholic (6)
Toronto District (33)
Trillium Lakelands District (16)
Upper Canada District (9)
Upper Grand District (4)
Waterloo Region District (7)
Wellington Catholic (1)
Windsor Essex Catholic (4)
York Catholic (9)
York District (17)



A Chance to Be Me

This inspiring 20-minute video focuses on three teenagers with varying degrees of ASD.

Share a day in the life of Chelsea, Sean and Brian. What makes these three unique is not that they have ASD, but that they have close friendships and acceptance in their school community. Join them at school, at home and in their communities learning what their daily life is all about.

ASO developed “A Chance to Be Me” as an interactive video to teach awareness to students and staff and to promote further in-class discussion. It’s an excellent opportunity for young people in Grades 6 to 12 to become more informed and be encouraged to interact with students who have unique challenges. With this awareness, comes empathy for all students with special needs and differences. This wonderful resource is available for a great price of \$25 and it’s all Canadian content.



Chelsea celebrates her starring role at the premiere of the video, A Chance to Be Me.

Alicia McPhail, narrator of A Chance to Be Me, attends Brock University in Child and Youth Studies and Linguistics



Chelsea Lesyk, student at Westmount P.S., Thunder Bay



Brian Piccini from St. Mary’s Catholic S. S., Hamilton

Students from Durham region were the panel participants in the video.

For this and other resource materials, check the ASO website at www.autismsociety.on.ca



Bike winners, St. Timothy’s P.S.



Financial Planning

Using RESPs for a Child with Developmental Disabilities

by Alison McQuilken, Legal Assistant, Law office of Kenneth C. Pope



To explore options for courses of study visit www.canlearn.ca

As parents, we do our best to help open doors that will provide our children with opportunities to continue learning. Children with developmental difficulties may not be interested in or able to attend university or college; however, this does not preclude their ability to develop other interests and skills through post-secondary education opportunities.

What is an RESP?

A Registered Education Savings Plan (RESP) facilitates a method of saving for post-secondary learning experiences by allowing you to earn investment income in a tax-deferred environment. Individual plans can be set up for the benefit of one beneficiary while Family plans accept contributions for more than one beneficiary.

The maximum annual contribution to an RESP is \$4,000 for each beneficiary. These contributions are not tax deductible. The federal government provides a grant of 20 cents for each dollar contributed, up to a maximum of \$400 each year and a lifetime limit of \$7,200. Recently they have announced that there

will be an additional grant for families with an income below \$70,000. The grant on the first \$500 contributed will be 40 percent for families with incomes below \$35,000 and 30 percent for families with incomes between \$35,000 and \$70,000. Contributions may be made for a period of 21 years and the maximum contribution for each beneficiary is limited to \$42,000. An RESP must be terminated by the end of the year that includes the 25th anniversary of the plan.

What if my child can't make use of the RESP 25 years from now?

Parents have always had the assurance that if their child decides not to pursue post-secondary education, their capital contributions to the savings plan would be returned to them tax free. They now have the additional assurance that up to \$50,000 of the income that accumulates in the RESP can be transferred into their RRSPs, to the extent that they have unused contribution room available.

Alternatively, parents can withdraw the RESP income and pay tax at their marginal rate plus an additional 20 percent, to offset the interest earned on the grant. The grant portion is returned to the federal government.

It is now also possible to roll over the educational assistance payments, without tax implications, to another family member, so long as the beneficiary is under 21 years of age and is related by blood or adoption. In the case of an RESP in the family plan format, educational

assistance payments can be paid out to another family member as long as the same qualifying criteria are followed.

How can the money be used?

To disburse the funds from the RESP, the education facility must be a "designated educational institution," with a "qualifying educational program." The school must qualify under the Canada Student Loans program or be certified by the Minister of Human Resources as an educational institution that will provide courses that will develop or improve skills in an occupation or vocation.

A "qualifying educational program" is not less than three consecutive weeks in duration and provides that each student spend not less than 10 hours per week on courses or work in the program. The in-class portion of a recognized apprenticeship can also be included. There are a huge variety of courses offered at post-secondary schools which meet these qualifications.

In order to make post-secondary studies more attainable, students with disabilities now have the option to attend school on a part-time basis. They can access distance education courses through correspondence, take part in online learning opportunities, or they can learn through a variety of apprenticeship programs.

Once the money from the RESP has been distributed to the beneficiary, the income earned in the plan, plus the amount of fed-

eral contributions, are taxed as income of the beneficiary. As a student, your child will probably not have much other taxable income and will be eligible for the tuition and education tax credits; therefore he or she will have little to pay in taxes.

What happens to ODSP?

While in pursuit of post-secondary education, Ontario Disability Support Payments, (ODSP) continue to be received by the child. These payments cover the cost of accommodation and food and are considered non-taxable income. RESP funds are used for tuition and books.

Although students with developmental difficulties face a number of challenges, most post-secondary learning facilities offer exceptional services for students with disabilities. I asked a student with Autism Spectrum Disorder who is in the Architectural Technician program at Algonquin College, what suggestions he would give someone in a similar situation. He replied, "I would encourage them to keep trying to meet their dreams and goals, and do not be afraid to ask for help."

Benefits

Registered Education Savings Plans are a practical tool which can be utilized for systematically saving funds to provide for a wide variety of possible post-secondary learning experiences, both for able students and for those who face a variety of developmental and cognitive challenges.

Disability Tax Credits

It's not too late

by John Dowson, Cb Ip, Executive Director of Life TRUST Planning

Did you know that as of October 1, 2004 there were only 92 days left to claim past Disability Tax Credits, before they expire forever? The Income Tax Act allows people with disabilities or their caregivers who have not claimed the Disability Tax Credit to reassess their income tax returns back to 1985. **On December 31 the new 2004 federal budget will cut off back filing beyond 10 years.** This means that people with disabilities or their caregivers will lose up to nine years of past tax credits.


People with disabilities or their caregivers who have not claimed the Disability Tax Credit should claim it now. It could save them thousands of dollars in income taxes they have already paid. More than 3,000,000 Canadians have a mental or physical disability and depend on someone for support. A dependent or caregiver may be a senior caring for a disabled spouse or common-law partner, a child caring for a disabled parent, or grandchild, grand-

parent, brother, sister, uncle, aunt, niece or nephew. Any one of these dependents or their caregiver is eligible to file for this tax credit. However many of these people are unaware of its very existence. If you or someone you care for has a mental or physical disability that is severe and prolonged, you may claim \$6,279 on your 2003 income tax return. Additionally, if they are under age 18, you may claim a supplement which provides for tax credits that are 50 percent greater. If you have never claimed this credit you can file back to 1985, *but only until December 31, 2004.*

Qualifying for the Disability Tax Credit is the yardstick that allows you or your caregiver to make further claims for a number of other tax credits, deductions and programs such as child disability benefits, education and tuition fees, attendant care, private nursing, private hospital, aids to daily living, dentures, hearing aids, prescription drugs, payments to adapt a vehicle, travel expenses for medical treatment, group home fees, prescribed therapy, talking books, tutoring, renovation costs and more.

If you have not claimed the Disability Tax Credit, do it now before you lose those extra nine years. It's not too late, yet.


You can help by lobbying the government to extend the deadline. If you read their website www.disabilitytax.ca, they make no mention that at the end of this year they will be taking thousands of dollars of tax credits away from people with disabilities, and yet this is confirmed in budget documents. Ask them to extend the credit adjustment deadline for families with disabilities by at least one year. Fax 613-943-5597, E-mail info@disabilitytax.ca Mail c/o Charles Smyth, Technical Advisory Committee on Tax Measures for Persons with Disabilities, 140 O'Connor Street, Ottawa, ON K1A 0G5. For further information, contact dowson@rogers.com or www.life-trust.com



Kenneth C. Pope

Barrister and Solicitor
Suite 500 - 251 Bank St
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K2P 1X3

- ✓Wills
- ✓Henson Trusts
- ✓Disability Tax Credits
- ✓ODSP Benefit Enhancement



Trusts are powerful estate planning tools that can maximize and protect your assets and your investments. A Henson Trust can protect a disabled person's inheritance without jeopardizing their right to Disability Support Payments. Experience security and peace of mind in knowing that your affairs are in order and that your loved ones are provided for.

Kenneth Pope travels across the province presenting seminars to assist families of children with special needs. His office also organizes monthly teleseminars in which parents can participate from home to benefit from Mr. Pope's extensive experience in estate planning, disability tax credits, wills and Henson Trusts. Family members, caregivers and supporting professionals are invited to contact his office to register for upcoming teleseminars. Space is limited. Reservations are required.

"Ken's clear and simple explanation of the Henson Trust and what is involved in setting one up enabled my husband and me to plan for the future of our special-needs son. ...My husband and I were appreciative of the fact that Ken took the time to come to Pickering to finalize our wills with us." - Mrs. L. - Pickering

"[Ken Pope] has shown a great deal of leadership and support to persons living with the effects of acquired brain injury. ... This has made a difference in the lives of many of those with whom we work." - John Kumpf, Ontario Brain Injury Association, on presenting Ken Pope with the "Legal Fellowship Award - 2002."

613-567-8230 - Fax 613-569-8989 - Toll free 1-866-536-7673 - E-mail kpope@kpopelaw.ca - www.kpopelaw.ca

Estate planning for families with children with special needs

by Kerry Wells, York University

“Our lab has found that children with autism can in fact be trained to use memory strategies.”

For more information on Dr. Bebko's memory studies or any of his other projects, or if you would like information on participating in a project, contact the Bebko lab at bebkolab@yorku.ca or at 416-736-2100 Ext. 20706.

Memory Strategy Use in Autism

Memory affects nearly every aspect of our lives. Most of life's tasks rely on information that we have memorized. It is not a singular concept as the term suggests, but actually consists of a variety of different and often independent skills. For example, one's ability to recall past birthday parties is a different skill from the ability to recognize a person whom you have previously met. Both of these skills however, are considered a type of memory.

Children and adults with autism often have deficiencies in some aspects of memory ability, but strengths in other areas. Ben Shalom (2003) notes that most of the literature has shown that individuals with autism demonstrate intact memory performance in the areas of rote memory and the recall of facts. In contrast, impaired performance has often been seen in the areas of source memory and memory for the sequence of events.

Another memory-related difficulty in autism is the inability to use strategies to improve recall (Bebko & Ricciuti, 2000), a critical skill needed for development of an individual's knowledge base. When someone tells us a phone number, we might repeat the number frequently to ourselves, a strategy that greatly increases the likelihood of recalling the number later. Research headed by Dr. James Bebko at York University has focused on trying to understand how individuals with autism use memory strategies, and how this skill can be further developed.

Most people are active when they process new information, which in turn, helps them to remember new data. In contrast, individuals with autism are more passive when confronted with new information, further exaggerating their memory deficiencies and giving the appearance of a deficiency in areas of memory that are actually intact (Bebko & Ricciuti, 2000). *If children with autism were more active when processing new information, all of their memory skills could be greatly improved, even in areas that may be more difficult for them.*

In typically developing children, strategy use emerges in the early school years (Rhee, 2000). However, like any newly emerging skill, the strategies are not used with great efficiency. The child, although producing memory strategies, may not actually be increasing their recall, or may be doing so only marginally, likely due to the high amount of cognitive effort required. As we age and develop, our strategy use becomes more sophisticated and automatic. Linguistic development is especially important because most strategies are language based. By the ages of seven or eight, typically developing children become much more adept at strategy use, and the skill becomes more ef-

ficient, providing greater facilitation of recall (Rhee, 2000).

One of the earliest strategies to emerge in young children is called *cumulative rehearsal*, cited in the telephone number example, where items to be recalled are repeated over and over in the correct order (Bebko, 2004). More sophisticated strategies that develop later include the categorization of items to be recalled, and the use of other mnemonics.

Children with autism, however, fail to develop strategy utilization in the same manner as typically developing children. For several years researchers had believed that children with autism simply failed to use memory strategies of any kind. However, they were rarely directly studied (Bebko & Ricciuti, 2000). Our research indicates that children with autism do develop the ability to use memory strategies. Despite this, the percentage of children with autism who use memory strategies is much lower than what is expected from their cognitive level (Bebko, 2004). In other words, when compared to a group of children that do not have autism, but have the same level of verbal and cognitive maturity, there are significantly fewer researchers among children with autism.

Strategy use may be delayed by several years in children with autism, and may emerge even later in those individuals with cognitive impairments as well as autism. *This delay has serious implications for their cognitive development, which may be further impaired because of the late emergence of this skill.* As noted by researchers Woody-Dorning and Miller, "the development of strategies is a main cause of memory development" (p. 543, 2001).

Recently we have explored the effectiveness of memory strategy training in children with autism, seeking to teach young children with autism how to use cumulative rehearsal, which was discussed earlier. This relatively simple strategy is useful in a number of situations. Since it is one of the first strategies to emerge in typically developing children, teaching it is developmentally appropriate, and may be used as a stepping stone to the development of other strategies. Rehearsal could quite easily be taught in a classroom setting.

Our lab has found that children with autism can in fact be trained to use memory strategies (Bebko 2004). Most importantly, *when these children are trained, the strategy is successful in enhancing their recall.* We have found that it is also important not only to teach the children the strategy itself, but also why they are learning this new technique and where else it might be used (Bebko, 2004; Rhee, 2000). These additional pieces are needed because of

the lack of planning and awareness of mental processes in children with autism. In addition, Bebko and Ricciuti (2000) found that the memory performance of children with autism is increased when maximum control of the learning environment is given to the child. This means letting the child process the material at his/her own pace, rather than presenting material at a predetermined rate. It is also well documented that external supports such as visual schedules, cues and reminders may be beneficial to these children.

Although teaching a memory strategy to children with autism may be a relatively simple task, they do seem to have problems maintaining this skill and generalizing its use to other contexts (Bebko, 2004). It is important to modify one's teaching techniques to maintain and generalize the strategy. We have found that it

Word Problems in Mathematics

Many students with Autism Spectrum Disorders (ASD) experience difficulty with word problems in mathematics. This difficulty can cause a great deal of stress for the student. A couple of years ago I literally woke up in the middle of the night with this approach to helping a student develop skills in this most challenging area. I hope that it proves to be helpful for your child or student.

- The ability to do word problems in mathematics is completely dependent upon a student's ability to read:
- The student must be able to understand the vocabulary/language of the problem.
- It may be necessary to target and teach specific vocabulary for problems. We cannot assume understanding of the terms.
- The student should have some confidence in her/his ability to perform tasks in computation.
- The student's fine motor skills should not be emphasized or perhaps even accessed during this learning process.
- In order to maintain a comfort level, work on a just a few word problems at a time, perhaps even one—depending on the student's willingness to engage, level of stress and perception of difficulty.
- Until the student is solving word problems with confidence, do not assign them as homework.

If it is deemed that solving word problems would be within the range of possibility for a student, there are several sequential steps that can be taken to help the student learn. These are:

- At the beginning of the learning process, use a consistent format, vocabulary and sentence pattern. eg.

is necessary to have several different training sessions—up to four or more—in which the child is taught strategy use, for children to be likely to retain the strategy at a follow-up session later.

We have also found that contrived situations such as delivering messages, or using commercial games that emphasize particular types of memory strategies, are generally more popular with the participants than simply attempting to recall a series of pictures.

Studies from the Bebko lab have repeatedly demonstrated that children with autism can be taught valuable memory skills. Improvement of memory strategies can lead to improvements in many areas including school activities and learning various routines that can have a lasting effect for the child.

- Mary has 2 apples.
John has 3 apples.
How many apples do they have?
- In the process of varying the problems, change their components in a sequential manner:
Change names:
Susie has 2 apples.
Billy has 3 apples.
How many apples do they have?
Change quantity:
Susie has 3 apples.
Billy has 5 apples.
How many apples do they have?
Change items:
Susie has 3 cookies.
Billy has 5 cookies.
How many cookies do they have?
Change verb:
Susie picked 3 apples.
Billy picked 5 apples.
How many apples do they have?

- As the student experiences success, these problem structures can be lengthened and made more complex. More variation can be added incrementally.
- This kind of sequence can also be followed for subtraction, multiplication and division.

While it would appear that learning to perform word problems could be a fairly lengthy process, this is time well spent. As students with ASD and other developmental disabilities progress through the grades, difficulty with word problems is consistently reported. For this particularly challenging task, it is worthwhile to take the time to create simple problems and spend time working on assisting the student to comprehend their demands and the operations needed to solve them.

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Rhee, T. (2000). The memory-metamemory connection in children with autism. Unpublished Master's Thesis, York University: Toronto, Ontario, Canada.
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by Leslie Broun, ASD
Consultant, Peel Board of Education



by Tamarah Kagan-Kusbnir,
MD, FRCPC – recipient of
ASO's Stimulus Grant 2004

Developing a new behavioural outcome measure

Many exciting advances have happened in the field of autism in recent years, with improved and earlier diagnosis being one of the most notable. New diagnostic tools have helped professionals recognize and diagnose children earlier and more accurately. Unfortunately, tools that rigorously assess whether treatments are effective for individuals with autism are lacking.

Behavioural difficulties are common in children with Autism Spectrum Disorders (ASD). They often create significant problems for the child as well as their family, teachers and therapists. Behaviour problems are a frequent reason why parents seek assistance from professionals, and difficult behaviours are often a target of intervention.

Our ability to assess whether a treatment works, as well as to develop interventions for specific, distressing behaviour, is currently hampered by a lack of appropriate tools to detect changes in behaviour. There are many behavioural questionnaires available, but few have been designed specifically for autistic children and as such are often inappropriate. Of those that were designed with autistic children in mind, some do not reflect recent advances in our understanding of ASDs. Others were designed for diagnostic purposes, and not to assess treatment efficacy. Parents have not been consulted in the development of any of these tools. As primary care givers, parents are experts in their children's behaviour, and ultimately are the ones who will decide if interventions are working.

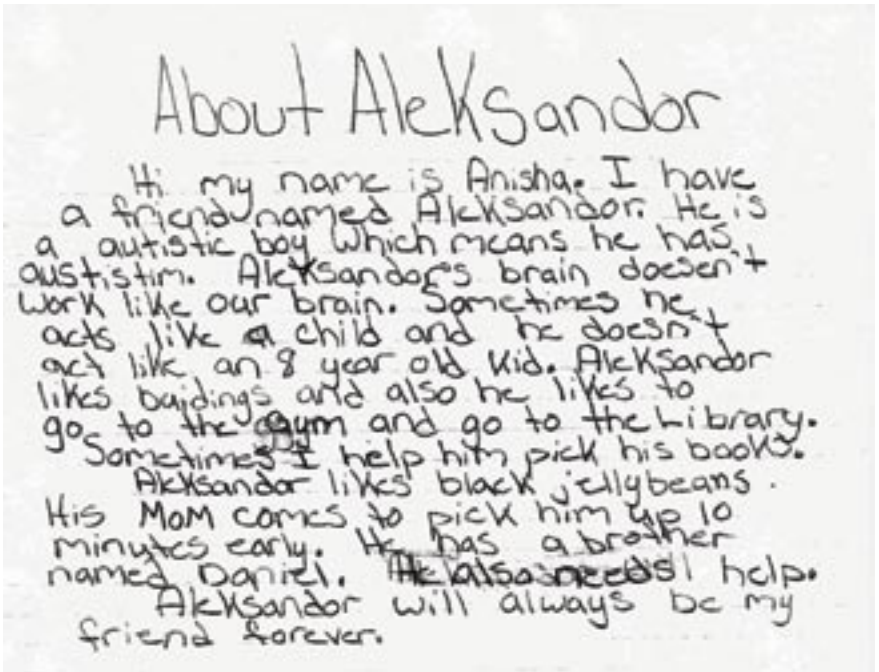
Developing a new tool or outcome measure that can detect changes in behaviour, is the focus of my research. The measure will be a parent questionnaire designed to be completed on successive occasions.

The project has multiple phases. The first stage, already underway, involves small focus groups of parents and professionals—people with first-hand knowledge about autistic behaviours and their impact on day-to-day functioning for the individual and their caregivers. The aim is to learn which behaviours pose difficulties or are a concern, so that these can be appropriately captured in the measure. Consulting with those who will use the tool will help to make it relevant.

The second part of the study focuses on gathering the list of behaviours generated and narrowing it to the most relevant and important. Additional focus groups and statistical methods will assist this process.

The measure will then be tested to make sure that it is user friendly, captures behaviours accurately, and is statistically sound. Future research will be done to assess how well it measures change in behaviour.

Autism Society Ontario's Stimulus Grant will help fund this research project, which I hope will improve our knowledge about what works best in treating children with autism. I am grateful to all the children who supported this grant through the *TOONIE FOR AUTISM DAY* campaign, especially to the families who have participated in my study so far, generously sharing their experiences, expertise and time.



▲ ASO Volleyball team rejoices after winning the Recreational 6's Consolation Round

RAAA! Volleyball Tournament

by Claire Woolford (Event Manager)

With everyone in high spirits, Autism Society Ontario took to Ashbridges Bay in Toronto for our first annual Raising Awareness About Autism! (RAAA!) Beach Volleyball Tournament. It was a beautiful day for our 11 participating teams who had worked very hard raising pledges for ASO. Everyone had lots of fun and team spirit was high as balls were bumped, set and volleyed in support of ASO. Participants were kept hydrated, well fed and treated by our many sponsors. Our thanks and appreciation go out to all teams who participated. Congratulations to our winners: recreational 6's *Nice Set* and competitive 4's *Sandy Chodas*. Every player walked away with a wonderful gift pack filled with donated goodies.

Our tournament could not have happened without the very generous support from our sponsors. We would like to thank:

- Mastercard Mosaik
- Pizza Pizza
- Hershey Canada
- Coca-Cola Limited
- Sanford Canada - Papermate
- 3M Canada
- Liberty Village BIA
- Ah-Shi Acupuncture and Complementary Medicine Inc.
- D. Scott Campbell & Associates Inc.
- Toronto Carpet Factory
- Shoppers Drug Mart
- Hawaiian Tropic
- Toronto East Sport and Social Club
- West Toronto Sport and Social Club

The event raised \$6,100 to support the work done by ASO to support children with ASD and their families. Stay tuned for details for RAAA! 2005. If you would like to be involved with RAAA! 2005 contact Claire Woolford at raaa_tournament@yahoo.com or call 416-618-1319.

Go Jays! Go!

July 26 was a great evening of baseball and autism awareness in Toronto. Over 30,000 fans showed up for the Toronto Blue Jays/NY Yankees game at Skydome. Thanks to Kathy Deschenes and Blue Jays Baseball Club (Ben and Cindy) who helped make this family day a reality. ASO staffers Ethel Berry and Esther Zhou handled ticket sales most ably.

ASO and various autism groups distributed 150 free tickets to parents, children and adults with ASD. Kim and Sara of KiSara <<http://heartfeltmusic.ca/kisara/index.htm>> sang beautiful renditions of the US and Canadian national anthems (lots of appreciative cheering fans). ASO had an information booth where we talked with Canadians and lots of Americans about ASD.

Thank you to everyone who was able to attend the game, who promoted ticket sales among friends, family and colleagues or who let us know they heard the radio ads on the FAN or saw the big electronic display board in downtown Toronto.



The 2nd annual (Wasaga) Beach Bunnies Ladies Golf Tournament,

held on June 26 at Marlwood Golf and Country Club, was a highly successful day. Event organizers, who want to make a difference in the lives of children with ASD, were thrilled to have doubled what they raised the year before. They are already making plans for next year's event.



ASO summer activities



▲ Kim and daughter Sara, better known as KiSara, singing the national anthems

◀ Luc VanderMeeren, ASO (Metro Toronto Chapter President and cross-Canada Cycle for Autism cyclist), throws the first pitch of the game

Margaret Spoelstra (left), ASO Executive Director and Ethel Berry (Manager) receive cheque for a portion of 385 ticket sales from Blue Jays' Orlando Hudson ▼



◀ Ethel Berry (in green) is presented the cheque by organizers (L to R) Gail Peterson, Marguerite Clost, and Marilyn Ruse. Absent from the picture is Helena Aherne

New Name! New Release! New Price!

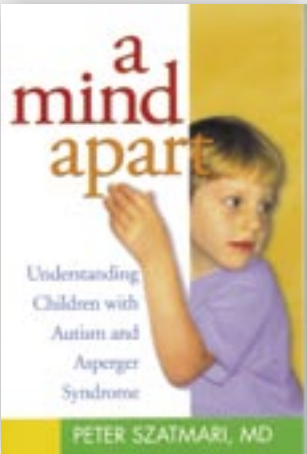
The video/CD, **Growing Up with Autism or Asperger's** is getting a makeover. It will be re-released under the title, **In Our Own Words** (same as the booklet). It is a collection of heartfelt stories that provide some insight and understanding into the lives of five adults on the autism spectrum, selling at an incredible price of \$20. Contact ASO at mail@autismsociety.on.ca or 416-246-9592 for purchase information.

ASO resources

by Anne Wittich, ASO Regional Support Leader



book review



ASD and Issues in Adulthood

The bright spot this year amidst the usual grayness of November will be the release of ASO's latest Manual: *ASD and Issues in Adulthood*.

This manual represents a collaboration of individuals and agencies committed to identifying and highlighting issues which adults with ASD in Ontario struggle with. The chapters within this manual provide examples of working programs across the province. Our partners in producing the manual are the Geneva Centre for Autism and Surrey Place Centre. Other contributors include Dennis Debbault, Liz Cohen, Elizabeth Bloomfield, Natalie Whatley and numerous others. Additional authors from Kerry's Place Autism Services are Kevin Stoddart and Gail Hawkins.

Contents include Person Centred Planning, Living Options, Recreational and Leisure Opportunities, Employment Issues, Post Secondary School, Social Skills, Safety in the Community

a mind apart

by Denise Copeland

I am pleased to have been privileged to review the book, *A Mind Apart*, written by Peter Szatmari, MD. Besides being written by someone very knowledgeable on the subject of Autism Spectrum Disorders, it was also a very humble, well-written book. I was intrigued at how willing and open Dr. Szatmari was to admit that he still had much to learn and how grateful he was to his patients who provided him with knowledge. His concern and caring for his patients is genuine and shines through in his words; he clearly wants to find out why autistic children think and feel the way they do. I found this to be a very inviting book, filled with interesting and helpful information. Having a child with Asperger's Syndrome myself, I found many similarities between the children mentioned in the book and my own son.

While this book contained a lot of useful information, it read like a novel and not a textbook, making it easy to keep the readers' interest. In one of the stories there was a little boy who was obsessed with death. I was touched by the way Dr. Szatmari used his knowledge, passion and resolve to figure out that the little boy was indeed concerned about the "change" that death brings, the possibility that he may need to get used to a new person when she dies, not death itself. It's this different way of looking at things that sets this doctor apart in my eyes. His evident caring seems to enable him, on some level, to think and feel like the children he is treating. As a result of reading this book, I feel that I now understand my child better; why he always asks questions that he knows the answers to and why he feels compelled to stay in the hallway at his sister's apartment building and listen to the hum of the elevator motor.

and Financial Planning for the Future. Examples of working programs in Hamilton and Toronto are included as well as personal accounts of individuals with ASD and their families.

Our hope is that families and individuals will be motivated to partner with government and non-government agencies to take the creative examples within these pages and adapt them to your own community needs. We also hope that this manual will help parents of younger children prepare for the years ahead.

The manual's theme is the ASO Vision—Acceptance and Opportunity for all individuals with Autism Spectrum Disorder.

In November we will launch this amazing effort formally. Look for announcements regarding this special event.

Funding partially provided by The Ontario Trillium Foundation, an agency of the Ministry of Tourism, Culture and Recreation, which receives \$100 million in government funding annually, generated through Ontario's charity casino initiative.

poetry corner

Messy Room
by Matthew Parks

In my room, I must confess
My room is a terrible mess!

Two banana peels, a plastic bag,
Stinky shoes, my dad's old rag.

An old poster, an apple core,
A wrapper, trust me, there's more.

A math test, my teddy bear
And a pair of my old underwear.

A twenty-five cent coin, a CN tower pass
And a book report that's due to class.

My pencil, a pen, a pack of cards,
A collection of pins that measures two yards.

Cookie crumbs, another pencil,
And one pack of four stencils.

Last but not least I must confess
A note from parents, "CLEAN UP THIS MESS!"

Matthew, an 11 year-old with Asperger's Syndrome, lives in Cavan.

Recipients of the Jeanette Holden Post-Secondary Education Entrance Scholarships for Siblings of Students with ASD

This award is in recognition of the role and contributions of the siblings to the welfare of individuals with ASD.

Matthew Holland is attending McMaster University in the Engineering program.



Jessica Boufford (with her brother Jordan) is registered in the Faculty of Social Science at the University of Western and plans to pursue her Masters in Speech Pathology.



Steven Waywanko, getting some welding tips from his brother Evan, is attending Confederation College in the Mechanical Techniques – Multiskilling program.



Eleanor Ritchie Post-Secondary Education Entrance Scholarship Recipients

This award is in recognition of the achievements of students with ASD in finishing their secondary education and enrolling in post-secondary education in Ontario

Mike Gignac (with his sister Danielle) is taking his Bachelor of Science program, specializing in Computer Science at the University of Windsor.



John Pyette has chosen to attend Seneca College to take the Library Technician Course.



Andrew Stutt, pictured with sister Casandra, is attending Algonquin College in the General Arts and Science Pre-Animation program.



Ian Scriver is taking Multimedia Design at Durham College.



Jenna Morris, with her parents and brother Terry, is taking Police Foundations at Algonquin College.

ASO Ontario Undergraduate Summer Student Scholarships

ASO is pleased to announce the names of recipients of the Undergraduate Summer Student Scholarship. This scholarship provides supplementary funds to individuals conducting research in any field related to ASD. Funds for these scholarships are provided through the TOONIE FOR AUTISM DAY campaign.

Dinh La is pursuing a BScH degree in life sciences at Queen's University, studying genetic influences in autism by testing DNAs from a large number of individuals with ASD (and their family members) in the Autism Research Program at Ongwanada Resource Centre in Kingston.

Colleen Mousseau is enrolled in a Psychology degree program in Social Science at the University of Western Ontario, working at the Offord Centre of Child Studies and researching the relationship between family stress and challenging behaviours exhibited by children with ASD.



Colleen Mousseau

In 2003, ASO established these scholarships to commemorate our 30th year as a province-wide organization. These awards are financially supported by our chapters and individual donations. If you would like to contribute to either of these scholarships, please send a cheque payable to Autism Society Ontario, 1179A King St. W. Suite 004, Toronto, ON M6K 3C5 Attn: J. Woolford. For information about the scholarships visit our website at www.autismsociety.on.ca

scholarship recipients

The Autism newslink



The Autism Newslink is a publication of Autism Society Ontario. Members of ASO automatically receive a copy. If you are not a member of ASO you can still subscribe to *Newslink*. Subscriptions cost \$25/year (published 3-4 times/year).

Please provide full mailing information and a cheque made payable to:

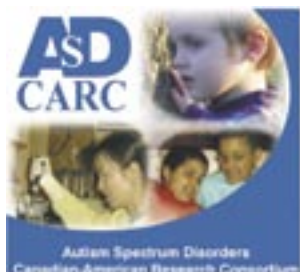
Autism Society Ontario
1179A King St. W., Suite 004
Toronto, ON
M6K 3C5
Phone 416-246-9592
Fax 416-246-9417

Note: The previous issue will be sent to you when you subscribe or you can check our website at www.autismsociety.on.ca.

New: In the Mohawk College Continuing Education, Learning for Life Calendar, the following course is offered. The course is fully subscribed and there is an extensive waiting list. Our thanks to the Hamilton-Wentworth ASO chapter for being an integral part of the implementation of this course. Watch for other courses offered around the province.

Autism Spectrum Disorder – Student Development EDUC10001

This course provides educational staff with the tools needed to work successfully with children diagnosed with this complex condition. It is delivered by a team of professionals from the local school boards & Hamilton Health Sciences Corp., including international autism authority Dr. Peter Szatmari. A strong emphasis will be placed on communication, social skills, behavioural challenges, family, sensory & educational issues. Students will be expected to attend a seminar at HHSC-Chedoke location.



Unraveling the Mystery of Autism:

From Genotyping and Phenotyping to Prospective Identification and Prevention

A research program of the
Autism Spectrum Disorders - Canadian American Research Consortium
(ASD-CARC)

Program Director: Jeanette J.A. Holden, PhD.

www.autismresearch.ca

Toll Free 1-866-ASD-CARC

ASD-CARC is a group of more than 60 researchers, clinicians, and parents from Canada and the USA working together to develop novel strategies for understanding ASDs and the effects of different treatments. ASDs are highly heterogeneous disorders, with both genetic and environmental factors. To identify these, we need to study a very large number of families - our goal is 10,000.

If you have one or more family members with an ASD, you can help us to **Unravel the Mystery of Autism** by participating in our research.

To participate in our research:

*Go to: www.autismresearch.ca or

*Call: 1-866-ASD-CARC or

*Contact Jeanette J.A. Holden, PhD

Professor, Depts. of Psychiatry and Physiology, Queen's University
Director, Autism Research Program

Ongwanada Resource Centre, 191 Portsmouth Ave.
Kingston, ON K7M 8A6

Funded by:



Research Studies

***Detailed Family Characterization:** ASDs are highly heterogeneous disorders, with both genetic and environmental influences. To subgroup families that are similar, we are documenting the family history, behaviours, responses to treatments, environmental factors, etc, through questionnaires and family photos.

***Genetics:** Together with the family characterization studies, we assess saliva or blood samples from family members to identify genetic differences that may contribute to developing an ASD.

***Infant "Siblings-at-risk" Study:** Infant siblings are at about 6% risk for developing an ASD and 20% risk for a social or communication problem. Our study involves identifying very early signs of ASD through interviews and completing developmental milestone checklists.

***Epidemiology:** There is much controversy surrounding the notion that there is an "autism epidemic". Our goals are to determine the prevalence and incidence of ASDs in different regions of Canada.