

# Exceptional

Vol. 6 No. 2 • Winter 2010

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OF EXCEPTIONAL CHILDREN

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ON THE COVER: Nine-year-old Spencer Lambert, of Winnipeg, plays the position of center for his sledge hockey team, The Sledgehammers.

## Cover Story

- 7 Canada's Other National Pastime**  
by LISA TABACHNICK HOTTA  
Why sledge hockey is the ultimate "equalizing" sport

## Features

- 11 SPD in the DSM: Why its Inclusion Matters to Us**  
by LORI FANKHANEL, REBECCA SUMMACH and BETTY DEAN  
Insiders shed light on life with Sensory Processing Disorder
- 18 Top Toys for Exceptional Children**  
by ERIKA CUCCARO, ALLISON FORSYTHE and CTTC STAFF  
The Canadian Toy Testing Council reveals the season's best buys
- 22 You Aren't the Boss of Me**  
by KATIE REINERT, MAHALIA WRIGHT and DAVE HINGSBURGER  
Taking control away from anger
- 28 The Child with "Delayed Speech"**  
by DR. JAMES COPLAN  
Ascertaining what constitutes typical development and what doesn't
- 36 Asperger Syndrome and my Learning Style**  
by NATHAN WEISSLER  
Strategies for teens with learning differences
- 40 Meet the Blogging Mamas**  
by AVIVA ENGEL  
Exceptional moms are taking the Internet by storm

## Columns

- 14 Ask the Expert**  
by VEETA ENGEL, MSW, MFT  
Teen seeks help around her sib's "embarrassing" holiday ritual
- 32 Sure I Can**  
by MICHAEL LIFSHITZ  
All I want for Christmas
- 44 In Focus**  
by HARRIET GREENSTONE, PhD, OPO  
The importance of psychological evaluations

## In Every Issue

- 5 From the Editor**  
by AVIVA ENGEL  
Life in perpetual Boxing Day mode
- 16 Exceptional News**  
News briefs highlighting special issues
- 25 Parentspeak**  
by LYDIA WORONCHAK  
Dreams can come true
- 31 Imprints**  
Karen Dubrofsky:  
Cooking for a cause
- 38 Currents and Classics**  
by AVIVA ENGEL and LAUREN SILVER  
A review of Carol Harrison's *Amee's Story* and Natalie Hale's *Managing My Money: Banking and Budgeting Basics*



11



18



22



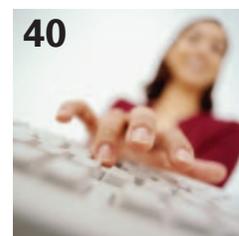
28



*Happy holidays from our Exceptional Family to yours!*



44



40

# Exceptional Family

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# Life in Perpetual Boxing Day Mode

**B**oxing Day. For some, the statutory holiday is considered almost as sacrosanct as the festivities that precede it. Whether Christian or Muslim, Jewish or atheist, we are all somehow united by the prospect of significant reductions on plasma TVs and brand-name skinny jeans.

As one who could have starred as the protagonist in Sophie Kinsella's *Shopaholic* series, I generally don't need much convincing to hit the mall – especially when there's a substantial sale going on. Ironically, though, the mall's the one place you'll never find me on Boxing Day. That's because years ago I reasoned that no deal, however great, was worth enduring the sensory overload that comes along with saving 60% on an already marked down pair of leather boots. Being wedged-in by hundreds of people, having my vision obstructed while overheating, and attempting to focus amidst the drone of shoving bargain-hunters and crying children, constitutes my personal sensory hell.

I imagine this is what it must feel like to live every day with Sensory Processing Disorder. While I can choose to stay home on Boxing Day, those with SPD are forced to live in perpetual Boxing Day mode – with no way out of the mall.

There is one small opening, however, for those touched by the disorder. It comes in the hope that SPD will be included as a bona fide condition in the upcoming fifth edition of the Diagnostic and Statistical Manual of Mental Disorders, or DSM – clinicians' and researchers' primary reference that categorizes and diagnoses a wide range of syndromes and cognitive disorders. We invite you to turn to page 11 to gain further insight into SPD and understand why its potential inclusion in the DSM is so significant.

On behalf of the Exceptional Family team, best wishes for a meaningful holiday season and a wonderful New Year. (And if you're bold enough to brave the crowds on December 26, a successful Boxing Day too.)

*Aviva*

**Aviva Engel**  
editor@exceptionalfamily.ca



PHOTO: JULIAN HABER



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PHOTO: ARIF JAFFER

# Canada's *Other* National Pastime

For players and fans nationwide, **sledge hockey is the ultimate “equalizing” sport**

by LISA TABACHNICK HOTTA

“**H**e shoots! He scores!” What hockey-loving Canadian hasn't heard (or uttered) this joyous phrase? For the millions of hockey fans across the country, there's a twist in the icy mix: it's called sledge hockey, and although geared for people with physical disabilities, the sport is scoring big among hockey enthusiasts nationwide.

Sledge hockey originated in Stockholm, Sweden, in 1961. It was introduced in Canada in the early 1980s, and today there are active leagues in nine provinces. The sport's rules and guide-

lines are surely familiar to many: sledge hockey incorporates the same rules and discipline structure as regular ice hockey, except that players sit on specially designed sleds, or sledges, equipped with skate blades under the seats. Rather than a single hockey stick, two sticks are used to pass, stick-handle and shoot the puck, and to propel and manoeuvre players' sledges.

## Making strides in Manitoba

In Manitoba, fans and players are particularly pumped up over the recent opening of Winnipeg's brand new MTS Iceplex, which includes a

sledge hockey-friendly rink – complete with sledge equipment and ice-lined player boxes enabling players to glide into resting posts with ease. Players' dressing rooms are located close to the rink, and can accommodate multiple wheelchairs.

For Manitobans, the Iceplex's accommodations for players with disabilities represents a huge milestone – considering that sledge hockey is a relatively new sport for the province altogether. Citizens owe much of their thanks for its introduction to Bill Muloin, the supervisor of Winnipeg's Children's Leisure and Recreation for the Society

for Manitobans with Disabilities. Almost four years ago, he founded Sledge Hockey Manitoba, an organization that runs both junior and senior sledge hockey leagues – The Sledgehammers, open to youth aged five to 17, and The Moose, whose players range in age from 18 to 50.

“My inspiration to bring sledge hockey to Manitoba came when I attended the Women’s World Hockey Championships

“We go the extra mile to make sure that someone can play. We’ll do just about anything to accommodate them.”

in Winnipeg, in 2007,” says Muloin. “During intermission, I saw an on-ice display from two of the Canadian National Sledge Hockey Players. I was truly awestruck at the grace, skill and power that this sport displayed. I knew then and there that I had to at least attempt to get this sport started in Manitoba,” Muloin recalls. “I began with no experience in sledge hockey and very outdated equipment, but one thing I did have was the determination that I was going to succeed at evolving this sport for athletes with and without a disability.”

While the league is open to anyone, youth and adults with physical challenges due to conditions like spina bifida, cerebral palsy, muscular dystrophy, amputations or stroke, are accorded priority registration over participants without disabilities. Muloin, his staff and many volunteers make every effort to encourage individual participation. “We go the extra mile to make sure that someone can play...we’ll do just about anything [to accommodate them],” he explains.

And the intricate and varied adaptations available to sledge hockey players are considerable. For instance, one Sledgehammer player who has limited upper body strength has an extra handle attached to the back of his sledge and a volunteer “pusher” who manoeuvres him around the ice. Another junior player with limited muscle tone also has a handle attached to the back of his sledge, as well as a harness system, and an extra hockey stick attached to the front of his sledge which facilitates his ability to stick-handle and shoot the puck.

### A sport for all abilities

For exceptional people who may be unable to participate in a typical game of ice hockey, the possibilities for inclusion in sledge hockey leagues are

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exciting. “If you have friends or siblings [without disabilities], you can all play sledge hockey together,” enthuses Muloin. “We’re slowly changing the barriers here,” he adds, referring to the sport’s added benefit of enabling exceptional people to showcase their skills and abilities. “It’s exciting that sledge hockey is now seen [by others] as a legitimate sport.”

Whereas regular ice hockey places strong emphasis on physical prowess and endurance, Muloin sees sledge hockey as the ultimate “equalizing” sport. “Once you’re on the ice, there are no wheelchairs, there are no walkers. You don’t know who has a disability and who doesn’t. You don’t know who has CP, who has spina bifida or an amputation – everyone’s the same. They’re all playing because they love the game. From an inclusive perspective that’s the pinnacle – providing a sport for all abilities.”

## Ice dreams

In a family where dad, mom and two sisters participate in ice hockey and ringette, Winnipeg-based Pam and Richard Lambert wanted their nine-year-old son, Spencer, to experience the similar exhilaration of participating in a sport on ice. Spencer has spina bifida – a birth defect that involves the incomplete development of the spinal cord or its coverings.<sup>1</sup> “It affects my legs below my knees,” explains Spencer. “I need AFOs [ankle-foot orthoses, or braces] and crutches to help me walk.”

After his family was introduced to sledge hockey at the Sami Jo Small Female Hockey Camp in Winnipeg, Spencer was inspired to join The Sledgehammers during the 2008-09 season. “It’s fun, challenging and I get to play with other kids on a team,” says Spencer, who typically plays the position of center for his team.

<sup>1</sup> [http://kidshealth.org/parent/system/ill/spina\\_bifida.html](http://kidshealth.org/parent/system/ill/spina_bifida.html)



Spencer and teammate Amanda Klassen, 21, (also pictured left wearing helmet) take a break during hockey practice.

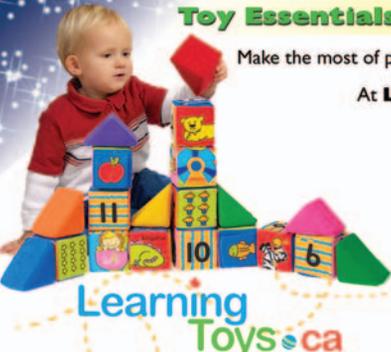
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PHOTO: ARIF JAFFER

Pam and Richard explain that they were drawn to sledge hockey because they felt it was a sport that enabled Spencer to actually play, rather than just sit on the sidelines. “Spencer is happy that he has *his* sport and he’s not always at the rink watching his sisters [play ringette] and wishing he could go out on the ice,” says Richard. “He is confident in his play...and he loves being able to do something physical that his body allows him to do.”

Spencer and his fellow sledge hockey players are proud to have their fair share of fans; having spectators and hearing the roar of the crowd makes any sport that much more exciting.

“I have everyone from my family – grandparents, aunts, uncles, cousins, friends and my parents’ friends – come out to see my games,” he enthuses.

### Sky’s the limit

More than just a sport, sledge hockey is bringing communities together. Men, women and children of all abilities are eager to get in on the action. Through their participation, they’re building stamina, making new friends and significant physical and emotional strides. Some even dream of future athletic achievements – including participation in regional and national competitions.

One of Manitoba’s senior Moose players was recently invited to the Canadian National Sledge Hockey Team Tryouts in Ottawa. The player had been in a car accident in his teens and broken his back. Prior to the accident, he had been a “high level” ice hockey-player, according to Muloin. Although he didn’t make the cut in Ottawa, the player was invited to join the national team’s Developmental Squad, enabling him to hone his skills further for a chance to try out again in the future. “As we know, life can change within seconds, and dreams can be extinguished [in an] accident,” says Muloin. “Sledge hockey has rekindled the dreams of some players, who, at one time may have thought these dreams would never be realized.”

Muloin and his staff are delighted by the role Sledge Hockey Manitoba plays in enabling both seasoned and novice players to dream big. “Our vision is to provide an opportunity for all individuals with disabilities to dream about reaching their goals,” says Muloin. “For some sledge players, the wish is simply to play a sport; for some it is to belong to a team. For others, it is to skate with their brother, sister or parent. For others it is to reach that golden ring of being the best player that he or she can be. Prior to sledge hockey coming [to Manitoba], youth and adults didn’t have that option [to dream]. A little fellow like Spencer has the dream of playing on the Canadian National Sledge Hockey Team. With hard work and perseverance, someday, [these players] might be on the podium for Canada. They’re ever-closer to achieving their goals.” ■

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*Eight-year-old Madison Fankhanel and her brother Jordan, 10, both live with Sensory Processing Disorder.*

# SPD in the DSM:

## Why its Inclusion Matters to Us

Insiders shed light on the efforts to get **Sensory Processing Disorder** into the **Diagnostic and Statistical Manual of Mental Disorders'** upcoming fifth edition

by Lori Fankhanel, Rebecca Summach and Betty Dean

If you've ever taken a psychology course, or are the parent or caregiver of an exceptional child, you're likely familiar with the Diagnostic and Statistical Manual of Mental Disorders, or DSM – the clinicians' and researchers' bible, of sorts – which is the main system used to categorize and diagnose a wide range of syndromes and cognitive disorders, including autism and ADHD. First published in 1952 by the American Psychiatric Association, the DSM's fourth edition is being revised, and the DSM-V is expected to be released in May 2013. While this is a couple of years away, the amendment process has already begun, and last February, draft changes were revealed and the public was invited to weigh in. Among the disorders short-listed for inclusion for the first time is Sensory Processing Disorder, or SPD. For people with the condition, and their families, the acceptance of SPD in the DSM would constitute a landmark victory.

## What is Sensory Processing Disorder?

Sensory processing, also known as Sensory integration or SI, refers to the process occurring in the brain that enables us to make sense of our world by receiving, registering, modulating, organizing and interpreting information that comes from our senses: taste, touch, smell, sight and hearing. We also use internal senses that tell us the position of muscles and joints (proprioception) and our position in space relative to gravity (vestibular). For example, when riding a bike, proprioception tells us which feet to push on the pedals and vestibular tells us when we are beginning to tip and which correction to make in order to stay upright on the bike. Our senses give us meaningful information about the world around us. In order to successfully ride a bike, prepare a meal or even read a book, we must process sensory information.

Sensory Processing Disorder (SPD), formerly known as Sensory Integration Dysfunction (SID), is a neurological disorder that results from the brain's inability to process information from one or several of the senses; in this case, sensory information is perceived abnormally.

Children who have difficulty interpreting sensory input may experience challenges in the following areas:

- *Activities of daily living*
- *Social and familial relationships*
- *Behaviour*
- *Physical coordination*
- *Emotional regulation*
- *Self-esteem*
- *Speech, language or motor skills*
- *Learning*

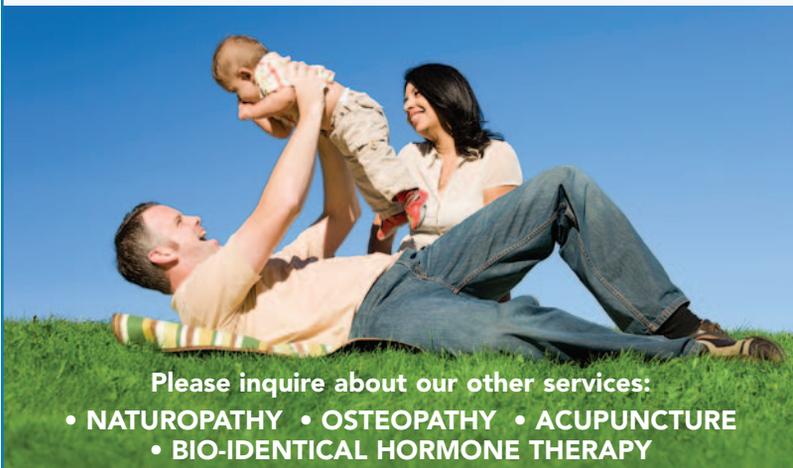
SPD can affect people in just one sense, or in multiple senses. Some people may be over-responsive (hyper-sensitive) to sensation, and find clothing, touch, noises or other sensory input intolerable.

Others may be under-responsive (hypo-sensitive) to pain, temperatures and touch. In over-responsive people, their condition may manifest in a dislike or refusal to wear certain clothing, a fear of feet leaving the ground or walking on uneven terrain, a fear of noises, picky eating habits, a negative reaction to smells and sensitivity to bright lights. Under-responsive people may have a high threshold for pain, enjoy spinning, love loud music, prefer food with intense flavour, have difficulty copying from the board and may be unaffected by strong odours.

The use of sensory information for function is a process that begins prior to birth and continues throughout our lifetime. SPD can affect children in numerous ways; many children can have multiple sub-types of the disorder. An assessment by an occupational therapist trained in sensory integration will highlight which areas of support and therapy a child needs. Other signs that your child may have SPD include:

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- *Poor motor-planning: difficulty performing and sequencing tasks, may appear clumsy, difficulty learning a new task*
- *Poor coordination: difficulty riding a bike or playing sports*
- *Social, emotional, play dysfunction: difficulty getting along with peers, accepting changes in routine, avoids eye contact, difficulty engaging in play and attending to tasks*

SPD can present with symptoms similar to ADHD and Autism Spectrum Disorders (ASD). As such, children who seek sensory input are often diagnosed and treated for ADHD as their behaviours are similar. Children with ASD may exhibit symptoms that are both over and under-responsive. Consequently, SPD and ASD are sometimes mistaken for one another.

According to Dr. Lucy J. Miller, a registered occupational therapist and founder and director of the American-based SPD Foundation, while SPD and ADHD are unique disorders characterized by different symptoms, some of the symptoms may overlap. Studies completed by the SPD Foundation suggest that although children with

ASD may have symptoms of SPD, most children with SPD do not have ASD.<sup>1</sup> Each condition is a distinct disorder.

## Living with SPD

When the process of interpreting sensory information is disrupted, decisions and behaviour may be compromised. According to the SPD Foundation, one in 20 people have SPD.<sup>2</sup> Potentially, then, there could be a child with SPD in every “mainstream” classroom; one can only imagine how these numbers multiply in a special education class.

Because SPD is not yet included in the DSM, the risk of misdiagnosis is great – sometimes resulting in the prescription of inappropriate medication or the improper placement of a child with SPD in specialized school programs for students with behaviour challenges or cognitive delays. In such instances, the school system becomes ill-suited for some families, and home-schooling is selected alternatively. This often leads a child to perceive of him or herself as a failure.

Just as critical and traumatic for families who live with SPD, is the isolation many experience as a result of the diagnosis. Children with SPD are often excluded from birthday parties, play dates and family gatherings. Medical doctors who are unfamiliar with SPD, and psychologists and psychiatrists with a lack of understanding and

knowledge of the condition, may label the parents as “neurotic” or identify them as having poor parenting skills.

## SPD as part of the DSM-V

The inclusion of SPD in the DSM-V will increase awareness of the disorder and its treatments among health professionals. Currently, it can be difficult to find an occupational therapist that is trained in administering the Sensory Integration and Praxis Test – the primary standardized assessment tool used for diagnosing SPD. Moreover, there are many OTs who do not consider SPD to be a bona fide disorder. The costs of therapeutic treatments are also more likely to be covered by insurance companies if SPD is listed in the DSM.

Whether SPD will ultimately be included in the DSM remains to be seen. Irrespective of the outcome, however, children and families will continue to experience the challenges associated with the condition. And parents will still persevere to do all that they can for their children. However, having SPD in the DSM will give these children and families a voice, a sense of empowerment, and an opportunity to lobby – with credibility – for their needs to be met. ■

**Lori Fankhanel** is the founder and president of Sensory Processing Disorder (SPD) Canada. She is the mother of two children with SPD.

**Rebecca Summach** has training in sensory processing disorders and treatment, and the administration of the Sensory Integration Praxis Test (SIPT). Rebecca owns Growing Changes Occupational Therapy Services for Children in Edmonton.

**Betty Dean** is the vice president of SPD Canada, a retired school principal and published author.

1 Miller, L.J. Sensational Kids. New York: G.P. Putman's Sons, 2006.

2 Miller, L.J. Sensational Kids. New York: G.P. Putman's Sons, 2006. Pages 273-279.

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For more information about SPD, visit [www.spdcanada.org](http://www.spdcanada.org)

To learn more about SPD's potential inclusion in the DSM, visit [www.spdfoundation.net/dsmv.html](http://www.spdfoundation.net/dsmv.html)



# Ask the Expert

## Teen Seeks Help Around Sib's "Embarrassing" Holiday Ritual

**Q** I'm 16, and have a 14-year-old brother with moderate mental retardation. Todd attends a special school where he's learning at a grade 2 level. Ever since he was a baby my mother has taken him to see Santa at our local mall. Despite the fact that he should have outgrown the activity years ago, he continues to ask to go every winter and my mother agrees. And each year I'm completely ashamed by the comments from friends who happen to spot them standing in line amongst the toddlers and their parents. (Having a teenage brother who visits Santa sure doesn't help my popularity.) I asked my mom how long she intends to give in to Todd and she replied, "As long as he continues to express an interest in going." I don't see why she can't just explain to him that Santa is for babies and he's now a man. It almost seems like my mom doesn't want to let her own baby grow up. How can I get her to see that she's being totally insensitive to my needs?



PHOTO: LAWRENCE CLEMEN

A column by marital and family therapist  
Veeta Engel, MSW, MFT

**A** Since in my experience it is uncommon for teens to take the trouble to write in for guidance, I know that having done so speaks of the extreme dread you are facing around your 14-year-old brother, Todd, visiting Santa.

There is no question that teens need to feel that they fit in with their peers; and Todd's behaviour supported by your mother appears to be getting in the way of this need. In order to help you to resolve this issue, I invite you to give some deeper reflection to what is really going on, for everyone involved: your brother, your mother, yourself and your friends.

First, let's consider Todd. You indicate that he functions at a much younger level than his actual age, learning at a second-grade level. Although you wonder why your mom doesn't explain to him that "he's now a man",

the reality is that in psychological, emotional and cognitive terms Todd is very little. Just as for most young children in our culture, the wish to visit Santa is extremely important to him. He has probably been building up anticipation for this event in the couple of months before Christmas due to the heightened excitement in the air in the holiday spirit.

Next, let's look at your mother's position. Of course she is aware that Todd is chronologically older than the kids who line up to see Santa. I doubt that she is having difficulty letting him grow up as you suggest, as much as it is likely her heartfelt wish for Todd to be age-appropriate, if only he could. Yet, despite this wish, she is willing to accept that Todd functions like a child on the inside and to respond accordingly. Like caring mothers everywhere, your mother wants to entitle her son to a pleasure that is in keeping with his

needs. This is more meaningful to her than what others may think when they see Todd in line at the mall. You are doing the important work of figuring out who you are as you move between childhood and adulthood. What anchors you at this uncertain time in your life is the safety of being accepted by your peers. And, when this is put into jeopardy as you describe, it can feel very uncomfortable if not downright threatening. Although you seek (and need) your friends' approval, there is another task involved in moving towards adulthood which is to learn how to differentiate yourself from the crowd. To know when it is time to lead rather than follow. To take a stand for what you believe to be right.

Finally, let's focus on your friends. It is an unfortunate statement about their own feelings of inadequacy that, despite what must be obvious to them about Todd's condition, they would

choose to act so heartlessly, causing you such distress.

Taking all these aspects into consideration, I am hoping that you will be guided to take a fresh look at the issue of your brother visiting Santa and your response to it.

Like caring mothers everywhere, your mother wants to entitle her son to a pleasure that is in keeping with his needs. This is more meaningful to her than what others may think.

Todd deserves to be accepted by you for who he is. His childlike spirit is one which many people, regardless of age or ability, strive to access through the



use of imagination and play. Your mother is choosing to meet Todd's wish to visit Santa not because she is being insensitive to your needs but more likely because she believes that you have the maturity and compassion to put his needs before your own – something which she is role-modeling for you in her own courage to ignore the potential derision of others.

And you must decide whether to allow yourself to feel shamed by the callousness of your peers or to build the self-respect that comes from standing up for what you know is right. When you begin to accept Todd, it will eliminate your friends' power to embarrass you. But more importantly, you will begin to experience the spirit of peace and goodwill which Christmas is meant to be about. ■

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Send your question to Veeta Engel for a chance to win a prize! Visit her page at [exceptionalfamily.ca/veeta\\_engel.php](http://exceptionalfamily.ca/veeta_engel.php) for more details!

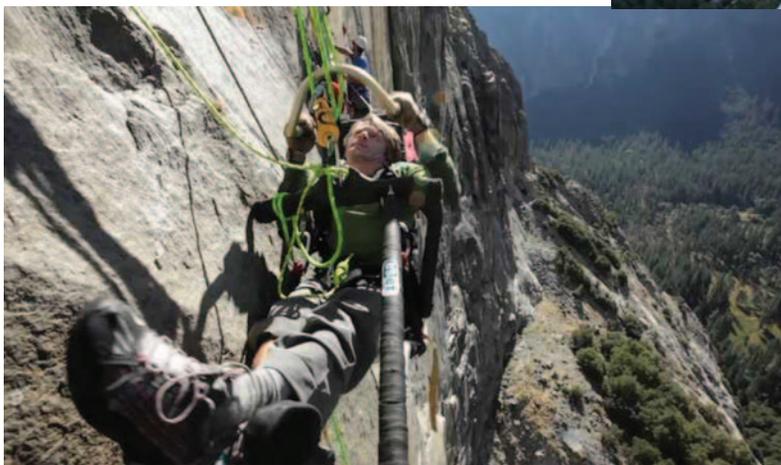


## Researchers uncover workings of genetic defect that causes cleft palate

Scientists at New York's Mount Sinai School of Medicine have unearthed the workings of the genetic defect that causes craniofrontonasal syndrome (CFNS), the disorder responsible for skeletal, brain and facial deformities, including cleft palate. While it has long been known that CFNS is caused by a mutation in the gene ephrin-B1, it was believed that the gene only guided the cells in craniofacial development. In studying mice with defective ephrin-B1 genes, however, Dr. Philippe Soriano and Dr. Jeffrey Bush of Mount Sinai discovered that ephrin-B1 actually controls the cells by signalling them to multiply. As such, when the gene has a mutation, the cell proliferation process becomes defective and in some cases disrupted, leading to craniofacial differences. Cleft palate affects one in every 700 North American infants. The scientists hope their findings will bring them closer to the prevention and treatment of the gene mutation.

## Man becomes first person with CP to reach mountaintop

A 42-year-old man with a previous fear of heights recently became the first person with cerebral palsy to reach the summit of El Capitan, a mountain twice the height of the Empire State Building, in Yosemite National Park. Stephen Wampler of Coronado, CA, spent six days scaling the granite face of El Capitan, a challenge he undertook as a fundraiser for his camp geared



for children with physical disabilities. The father of two trained for a year in order to muster the strength needed to pull himself up four to six inches at a time in a special wheelchair. Two of his friends assisted him with the ascent, while a group of Marines took shifts carrying Wampler down on their backs. Wampler still hopes to raise the \$2 million he aimed for, via a new documentary about his journey slated for release in the New Year.

## Your child may not have ADHD after all

Of the 4.5 million American children with ADHD, approximately one million may have been misdiagnosed with the disorder simply because they're among the youngest and least mature in their class, a Michigan economist proposes. As reported in USA Today, Todd Elder, assistant professor of economics at Michigan State University, studied the variation of ADHD diagnoses in 12 000 kindergarten students, aged five and six. He found that the youngest kids in the grade were 60% more likely to be diagnosed with the disorder than the oldest ones.



According to Elder, the children's inability to sit still during class may simply have been a consequence of their emotional and intellectual immaturity relative to their older peers. Elder also suggests that the children's diagnoses were influenced by teachers' recommendations that they be assessed for ADHD. The findings have raised concern about the psychological and physical implications of being unnecessarily labelled and treated for a disorder.

## Kids invent comic book superhero that uses a wheelchair



Liquid Comics recently unveiled a new character with a disability, thanks to a group of exceptional American and Syrian youth who conceived the idea, the Associated Press reports. The youngsters gathered in Damascus over the summer to discuss their vision for a new comic book superhero as part of the Open Hands Initiative, an American non-profit organization dedicated to "international friendship", "basic shared values and common humanity". The kids came up with *Silver Scorpion*, a Muslim boy who lost both legs in a landmine accident. He uses a wheelchair and can control metal with his mind. The character's adventures will be available in both English and Arabic.

## Solution's as plain as the nose on one's face

In the near future, people with severe paralysis may be able to communicate and steer their wheelchairs simply by sniffing, thanks to a unique device developed by scientists at Israel's Weizmann Institute. Sniffing is a motor skill that is partly controlled by the soft palate. Operating on the hypothesis that one's ability to sniff is maintained even in the most severe case of paralysis, Professor Noam Sobel and his team created an apparatus that interprets changes in air pressure in the nose and translates them into electrical signals in order to execute various tasks. Functional Magnetic Resonance Imaging scans confirmed their theory, and actually highlighted an overlap in certain areas of the brain that control the soft palate and those that influence language.



The device responds differently to sniffs that are exhaled, inhaled, long, short, shallow and strong. When operating a wheelchair, for example, two consecutive sniffs direct it to go forward; two sniffs out direct it to move in reverse, and so on. Sobel hopes the apparatus may also be utilized one day by pilots and surgeons to control "third arms".

# Top Toys

## FOR EXCEPTIONAL CHILDREN

Looking for a great holiday gift?  
The Canadian Toy Testing Council can help!

by ERIKA CUCCARO, ALLISON FORSYTHE and CTTC STAFF

With the holidays just around the corner, families are in full toy-buying mode, searching for just the perfect gift for the children in their lives. When facing aisles of colourful offerings, the selection can be overwhelming. That's where the Canadian Toy Testing Council (CTTC) comes in.

The CTTC is a non-profit organization that is sponsored by Energizer Canada Inc. It also receives funding from the Ontario Trillium Foundation, an agency of the Government of Ontario. But it's the volunteer families and children that really make this program successful.

Every year, the CTTC selects hundreds of new toys to be evaluated in its internationally-recognized toy-testing program. Volunteer testing families assess each toy's design, function, durability, safety, and play value. Canada's leading experts in toys – children – play with the toys in their homes for six to eight weeks and caregivers evaluate the toys' performance. The CTTC then rates each toy – awarding Three Stars, Two Stars, One Star, or Not Recommended. Toys earning Three Stars have been rated as Very Good to Excellent in all categories and are eligible for CTTC awards, such as the Energizer Toy of the Year award, the Children's Choice awards and the Best Bet awards.

Tracy Schmidt, of Ottawa, is one of the many dedicated CTTC volunteer toy testers. Schmidt evaluates toys with her own children at home as well as with the students in her elementary school classroom. An educator with 12 years of experience teaching junior and intermediate school-age children with autism, Schmidt emphasizes that there are many great toys on the market for all ages and stages. She believes that parents know best what their children will find attractive and fun.

The CTTC recommends the following award-winning, Three Star toys as excellent gift ideas for all children, including those with cognitive and/or physical limitations. In addition to meeting the CTTC's evaluation standards, these toys were also tested extensively in Schmidt's classroom.



## Balancing Bug Stacker

*(Lamaze by Learning Curve; Developmental ages 6 to 12 months, \$22.95)*



This appealing play set includes six colourful, textured bugs that stack together with magnets. The bugs are chunky and easy to stack, so children with developing hand-eye coordination and visual-motor planning can successfully connect them with the help of the magnets. The bugs can be piled and pulled apart over and over again. Colour recognition and basic numbers (1-6) are also skills that can be practiced. Play can extend to patterning and matching with the addition of one or more sets. "I would often put the magnets together and have my students pull them apart as a fine-motor activity," notes Schmidt.



## Teach My Baby

*(Teach My Inc.; Developmental age 6 to 18 months, \$49.99)*

This 66-piece kit includes puppets, puzzles, blocks and cards to help explore self, sound, touch, first words and numbers. "I had students who were developmentally a little older, but still needed to practice the skills that are taught and reinforced by this resource," explains Schmidt. "It was great for one-on-one interaction and focused educational play." The teaching tools include pictures of multi-cultural children that Schmidt's students loved. "I used the pictures to teach basic vocabulary," she says. "Teach My Baby provides lots of opportunity to teach matching, which is a pre-reading and math skill. It is very well designed!"

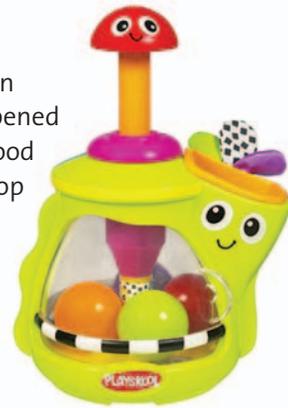


3

## Explore 'n Grow Tumble 'n Twirl Top

(Playskool/Hasbro; Developmental age 8 months+, \$21.99)

Children push the plunger down and watch the balls inside spin round and round. When the balls spin fast enough, the door can be opened and the balls will fly out, to kids' delight. The plunger and balls are a good size for small hands to grasp. A highly attractive and exciting toy, the top stimulates motor planning, hand-eye coordination, visual perception, and fine-motor skills. "This toy is a hit with my students," says Schmidt. "They can't get enough of it!"



4

## Teach My Toddler

(Teach My Inc.; Developmental age 18 months+, \$49.99)

This all-inclusive kit contains a handy parents' guide and materials that may be used to expand upon the skills learned in the "Teach My Baby" set. A wide variety of tools including a book, poster, puzzles and flashcards are geared to teach concepts such as the alphabet, counting, shapes, and colours. "I like the fact that all the items are in one compact box," notes Schmidt. "There are definitely other puzzles, flashcards and posters available, but the beauty of Teach My Toddler is that everything is coordinated. It is a great resource for reinforcing learning through labelling and matching."

5

## Wedgits Starter Activity Tote

(ImaginAbility; Developmental age 2 years+, \$24.99)

Wedgits are brightly-coloured, sturdy building blocks that nest together. This tote includes a set of design cards in a range of skill levels, and blocks that come in a variety of sizes. "The large chunky pieces are easy to manipulate and are great for children with low [muscle] tone," says Schmidt. "The smaller the pieces get, the more challenging they are to wedge. Some assistance may be required until finger strength and problem-solving skills develop." As well as being fun to play with, Schmidt found the set optimal to hone a variety of skills such as hand-eye coordination, following directions, visual-motor integration and sequencing.



# 6

## Kidijamz

(Vtech; Developmental age 3 years+, \$49.97)

This keyboard-style DJ play centre has everything children need to make, record, replay, and perform their own music. Kidijamz was tested by exceptional mom Joan Kavanagh-Wilson, of Ottawa, and her son, Cameron, who has cerebral palsy and developmental delays, and is blind. Cameron’s love of music made Kidijamz the perfect toy for him. “The keyboard keys light up when pressed, which is good for children with low vision,” notes Kavanagh-Wilson. “The knobs, buttons, and scratch disks are easy to manipulate, which is an important consideration for children with fine-motor difficulties.” The durable toy has slots on the bottom to allow it to be tied to a surface for stability. Kavanagh-Wilson attached the toy to a table using cable ties, so Cameron could operate it without having to worry about it sliding around. “Cameron loves sitting in his wheelchair at his own studio and creating a variety of musical pieces,” she says.



# 7

## Cariboo Island

(Cranium; Developmental age 3 years+, \$24.99)

Children explore the island of Cariboo in search of coins to help them unlock a treasure chest.

During the hunt, anticipation grows and erupts in great excitement when a player finds a coin.

The key used to open the doors is a

good size and it’s chunky, making it easy to grasp for children with fine-motor difficulties. Instructions are simple and the game encourages turn-taking and basic skill development of colour, number, shape and letter recognition. “My students loved this game and asked to play it again and again,” says Schmidt.

Regardless of a child’s developmental level, the play value of many toys often extends beyond the recommended age listed on the box. Schmidt believes that parents should always make time to sit with their child and discover how to play with any toy. “Engage your child and explore together,” she says. “Playing is open-ended and it’s as much fun as you make it.”



For testing results on hundreds of new toys, check out the 2011 CTTC Toy Report, at [www.toy-testing.org](http://www.toy-testing.org).

# You Aren't the Boss of Me

## Taking control away from anger through anger-management training

The second in a series on Living, Loving and Relating presented by Exceptional Family and Vita Community Living Services, an organization serving adults with intellectual disabilities in the Greater Toronto Area

by KATIE REINERT,  
MAHALIA WRIGHT  
and DAVE HINGSBURGER

### *“I can't stop!”*

She is clearly distressed. In the aftermath of a huge temper tantrum, she feels powerless. To her, anger is something that takes away her sense of control. When discussing the situation in an anger-management class, she was asked, “What could you have done other than breaking things and yelling?”

She was stunned. “There's something else I can do?”

For the past several years, Vita Community Living Services has offered anger-management classes for our members with disabilities, and care providers. Members are always relieved to learn that there are healthy strategies and alternatives for dealing with one's temper, rather than acting out; for

many, tantrums were previously their only means of expression when upset.

### *“It's not ok to be angry – I'm supposed to be happy.”*

Many individuals with disabilities have learned that their anger is unacceptable and that what is wanted of them is passive acceptance of all that comes. But both they and care providers must recognize that anger is simply one of many emotions that, like others, serves a purpose. Anger alerts us to the fact that something's wrong. Anger motivates and

energizes us to be assertive and speak up. Anger, used properly, prompts self-advocacy. Acceptance of anger as an appropriate response to untenable situations is a very big step toward mastering emotional self-regulation.

As the course teachers, we've learned a lot about our members and the lives they lead. This has contributed to an important realization: the disability experience is one that carries frustrations, obstacles and disappointment –



realities that constitute typical anger triggers for most people. In order to assist members and care providers to better manage their emotions, we compiled the following anger-management strategies:

## Tips for Care Providers

### 1 Go ahead and be angry!

You are a powerful role model for your child. He or she needs to see you deal with anger in a positive manner. When you return home frustrated after a long ride stuck in traffic, for example, share your feelings with your child and model appropriate calming techniques: "I'm really angry. The traffic was bad and I got cut off twice. I need to sit down and take a breath or two."

### 2 Don't let anger work

Sometimes anger is employed as a means of control. Your child may offer you a deal: "I'll calm down when you give in." This can't work. As much as it may be tempting to relent for the sake of achieving momentary peace, it is important to follow the basic rule of, "When you calm down you can/we can..." By requiring calm before negotiation or discussion, you are teaching that issues are best dealt with in an atmosphere of respect.

### 3 Let negotiation work

Flexibility may be the most important "ability" of parenthood. Your child needs to learn that if he or she wants to delay a chore until after a television program, the best way to achieve this is via discussion, not tantrums. Sometimes the discussion might lead to changed plans or expectations, which will underscore to the child that calm discussion is more likely to yield desired results than angry outbursts.

But be prepared to really hear what your child is saying. There is no point teaching someone to talk through their problems if no one is willing to listen and respond.

### 4 Develop a code word

Once your child has devised a strategy for dealing with anger, choose a code word that you will refer to, to remind him or her to use it. During a period when your child is calm, have him or her recall a favourite memory or time of genuine happiness, then think of a single word (like *beach*, *trampoline*, or *dancing*) to remind your child of that memory. Rather than nag your child when he or she is angry to "walk away" or "breathe" – which may exacerbate the situation – a code word is a more discrete reminder to your child to take control of his or emotions on his own.

### 5 Anger-management is a skill

Skills take time and practice to master. Your child will need time to learn to employ the strategies you devised. Occasionally it may also appear that he or she isn't "getting it". Repetition is key; every time your child uses a strategy or chooses to remain calm in the face of an anger trigger, offer positive feedback in the form of praise. Employing these strategies is hard – for all of us. As a species we've tried to deal with anger positively for centuries; the

17<sup>th</sup> century Roman poet Horace once said, "When angry, count ten before you speak; if very angry, one hundred."

## Tips for People with Disabilities

### A Recognize triggers

Stressors constitute different things for different people, and everyone deals with stress in their own way. It's important for your child to review times when he or she has gotten angry and to identify the primary cause of the anger. Was it frustration or disappointment around cancelled or changed plans? Once the trigger has been determined, the child can be taught to be on guard and ready to use his or her strategies when the situation arises again. This preparedness will contribute to a sense of personal self control, an "I-can-handle-this" sense of maturity. For your child, knowing that there are options in the way he or she chooses to respond will make situations less catastrophic and more hopeful.

### B Recognize physical messages

A surprising number of people taking the anger-management classes at Vita were not aware that anger often manifests with physical symptoms. Increased heart-rate, rapid breathing, flushed

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cheeks, tense shoulders and clenched stomachs, may all indicate to someone that they are becoming angry. Being aware of one's physical response to anger enables an individual to preemptively employ a coping strategy before he or she loses control. Sometimes a care provider can assist with this by using "non-verbal paraphrasing" (i.e. "I can see you are getting angry because your shoulders are tensing up"). This way the individual begins to understand that anger affects body first and behaviour second. In between body and behaviour is opportunity for decision-making and problem-solving.

### **C** Identify a strategy

There are three main strategies for anger control: buying time, calming down, and escaping the situation. Each of these may be achieved in a variety of ways: counting to ten (buying time) is recommended in almost every anger-management class. For people with disabilities who may have difficulty counting, an adaptation might be to "find everything that's brown in the room." Taking a few slow breaths (calming down) works well if a person knows gentle breathing techniques. Taking a quick time-out in the bedroom (escaping

the situation) works wonders as well. But the end result of all of these needs to be discussion and negotiation. It is through these that an individual learns the difference between assertion and aggression.

### **D** Problem-solve

When a strategy does not work, problem-solve and brainstorm other ones. Don't give in to failure. Consider approaches that might work in the future, and emphasize the positive in the fact that anger has been identified as a problem and solutions are being sought. If one strategy doesn't work, another just might.

### **E** Develop inner language that encourages

Positive self-talk is tremendously powerful. Your child needs to be his or her own personal cheerleader. Learning to say inwardly, "I know I can handle this", or "I am in control of my feelings", or "I'm going to get this problem fixed", all contribute to a child's self-esteem and expectations of personal success. It's important to be positive within so that changes can be made without.



Anger-management classes are aimed, then, at ensuring that anger's "purpose" is not lost. They are meant to teach the individuals in attendance to assert themselves and negotiate for change. Anger-management is not anger suppression. Nor should anger management ever be used for control, or to encourage passivity. Most members who come to the classes know that the environment is a safe place to discuss what bothers them. It is also a place where they can experiment with anger-management strategies. They know that they are learning and don't expect instant success, but gradual change. Most of all, they learn that they have a right to their feelings and a right to be heard. ■

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**Mahalia Wright** is a Day Program Instructor and Anger-Management Trainer at Vita Community Living Services. She has worked in the Open Custody with Youth in conflict with the law, where she was also a UMAB (Understanding and Managing Aggressive Behaviour) Trainer.

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## Dreams Can Come True

by LYDIA WORONCHAK

Something unexpected happened during my last pregnancy. I always took for granted that my children would be healthy. I never stopped for a moment to think that one of them might be born with a chromosome disorder.

I met my future husband, Claude, while volunteering for the Quebec Special Olympics (QSO). At the time, I was completing my Bachelor's degree in Exercise Science specializing in Adapted Physical Activity. I had made up my mind that I was going to work with people with disabilities. But I decided to put my career on hold and have a family first. Within eight years of being together, Claude and I had four healthy children.

We had also decided to put off getting married until all of our children would be able to take part in the ceremony. It was our dream.

In 2005, we decided to have one last child. I became pregnant and we were thrilled to find out that we were going to have another girl (we had three sons and one daughter at that point). But our excitement was short-lived; during a routine obstetrical sonogram, the technician noticed that one side of our baby's heart was bigger than the other and recommended that I go for a cardiac sonogram at a specialized hospital just to be on the safe side. I felt panic. Claude was in disbelief.



*A memorable day: sisters Renata, 4,  
and Sabrina, 2, at their parents' wedding.*

I knew in my gut that something was wrong and I feared the worst.

The sonogram confirmed that my baby had truncus arteriosus,<sup>1</sup> a severe heart defect. I couldn't believe it was happening to me. By this time I was already in my third trimester. I had an amniocentesis to find out if the heart defect could be related to a genetic disorder and the results indicated that my baby did in fact have a chromosome deletion disorder known as DiGeorge syndrome (22q11 deletion), a rare genetic disorder affecting one in 4000 births. I had never heard of this syndrome before. It felt as if my whole world was falling apart and my dreams were shattering before my eyes.

After discussing the implications of DiGeorge syndrome at great lengths with geneticists, we questioned what kind of life our child might have with a condition marked by distinct facial features, palate abnormalities, learning difficulties, speech problems, recurrent infections, feeding difficulties, hearing loss, and the possibility of autoimmune and psychiatric disorders (such as schizophrenia) later on in life. We were told by my childhood pediatrician that keeping this baby would destroy our existing family. Aside from her severe heart problem, which would necessitate several surgeries during the course of her life, we had no idea what the future held for our daughter.

I worried if she would make it to term as there was a poor oxygen exchange in the womb. I wondered what she would look like. I wanted to see another child with the same disorder before my daughter was born, but it was impossible due to doctor-patient confidentiality. I could only look at pictures online. Not knowing what to expect was difficult.

<sup>1</sup> A rare type of congenital heart disease in which a single blood vessel comes out of the right and left ventricles, instead of the normal two (pulmonary artery and aorta). ([www.nlm.nih.gov/medlineplus/ency/arti cle/001111.htm](http://www.nlm.nih.gov/medlineplus/ency/arti cle/001111.htm))

We chose our daughter's name with the help of her siblings before she was born: Sabrina Karyna Rebecca. It was the only thing we knew for sure; no matter what happened she was a person – our Sabrina.

We did all we could to ensure the best possible outcome for our daughter. We met with a cardiac surgeon prior to her birth. I was followed by a high-risk gynecologist for the remainder of the pregnancy. And when Sabrina was born on April 22, 2006, a medical team was ready for her arrival, to offer immediate care.

I only got to hold my baby for a moment and get a glimpse of her before she was whisked off to neonatal ICU. I felt as though my heart had been ripped out of my chest. I felt helpless. That was the beginning of our journey.

Sabrina had her first corrective heart surgery at 10 days old, and numerous complications followed. She had been intubated from birth, and was unable to be taken off of the ventilator. Six weeks later, we were told that she didn't have much longer to live.

She couldn't die now – we loved her. We had to keep fighting for her and believing in her. We couldn't give up on Sabrina or our dreams.

A second open-heart surgery was necessary to repair her leaky aortic valve. The surgery went well but there

were still many complications. Sabrina, now eight weeks old, continued to fight. Standing by her bed in the NICU, we told her that we wanted her and needed her, and all about her siblings who were waiting for her to come home. They loved her even though they had never been able to see her in person since she was born; all they had of their sister were pictures.

Seven months later, Sabrina was still in the hospital and still unable to come off the ventilator. We resolved to try one last resort: another open-heart surgery to give her a mechanical aortic valve. This was at the end of January 2007. Once it was over, things finally began looking up. Sabrina recuperated within a matter of weeks and by March, was being transferred to the ward to continue the recovery process. She was finally off the ventilator but still needed oxygen. Just as we were getting closer to our goal of bringing her home, there was another setback: Sabrina suffered cardio-respiratory arrest and, within moments, all of the progress she had made seemed futile. We were back at square one. We felt as though we had lost the Sabrina we had come to know and love. She was at her all-time low.

Despite the medical consensus that Sabrina would probably never fully recover, we continued to believe in her. One special, dedicated nurse refused to give up on our daughter and helped us to keep believing that she could make it home someday despite the odds against

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Claude Blanchard and Lydia Woronchak celebrate their marriage together with their children Jean-Claude, 10, Sabrina, 2, Jack, 6, Renata, 4, and Marc-Andre, 8.

her. We were also blessed to have a devoted ICU pediatrician whom we could approach with any questions or concerns throughout Sabrina's long hospitalization. After almost 14 months in the hospital, a miracle occurred: our baby finally came home.

The day Sabrina left the hospital, she was sent home in palliative care and given "one day." It was never clear to us if that meant one day to live or one day at home before she would have to return to the hospital. But Sabrina is a survivor. The following year was very difficult, with frequent hospitalizations and visits to specialized clinics. It was

an adaptation period for all of us. The fear that she might pass away due to an infection or heart failure consumed us with worry. However, we tried to maintain a positive attitude and enjoy every moment we had with her.

Today Sabrina is four. She continues to do well, progressing at her own pace. She may have a significant developmental delay in addition to feeding problems and recurrent infections, but we rejoice in her achievements. We treat her like our other children. We continue to support her and ensure that she has the best possible services to obtain the best possible outcome.

She is just beginning progressive entry into a specialized school program for four-year-olds; a milestone that once seemed impossible.

Sabrina is surrounded by an incredibly loving family. That love is what has helped her to overcome so many obstacles and what will continue to help her in the future. Sabrina did not destroy our family. On the contrary, she brings so much joy to all of our lives and to everyone who meets her. She has taught us so much about life.

Sabrina is our "exceptional girl". Our children know she has DiGeorge syndrome and that doesn't matter to them. They love her with all of her differences and special needs. And when they do have questions about her, we try our best to answer them as honestly as possible.

On September 13, 2008 Sabrina got to be the junior flower girl at our wedding. It just goes to show that dreams can come true. ■

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## The Child with

# “Delayed Speech”:

## Ascertaining what Constitutes Typical Development and what Doesn't

by Dr. JAMES COPLAN

“Delayed speech” is a common concern in toddlers and preschool children. Under normal circumstances, children begin saying “mama” and “dada” by 10 to 11 months of age, and at least one single word other than mama or dada by their first birthday. By age two, a child should have over 50 single words, and should begin producing spontaneous, novel two-word phrases such as “Want bottle” (not just phrases that have been taught and memorized as a unit, such as “I love you”). Between two and three years, children produce three- to five-word phrases, omitting tense endings (such as “ed” or “ing”), articles, conjunctions, and other small “helper” words. An example of such “telegraphic” speech would be a sentence like “Daddy go store?” By this age, the child’s vocabulary is too big for most parents to count. By age three, a child should be producing simple, grammatically-correct sentences. The clarity or intelligibility of a child’s speech also improves over time; unfamiliar adults have about a 25% chance of understanding what a one-year-old says, 50% of a two-year-old’s speech, 75% of a three-year-old’s speech, and essentially all of what a four-year-old says.

### The many facets of communication

Language is more than just speech. Speech is one aspect of communication, but when assessing a child with “delayed speech,” we need to consider whether the child may actually have delayed *language*, including *receptive* and *visual* communication skills. Key receptive milestones (i.e., the ability to understand others) include recognizing one’s own name (nine months), following one-step commands (12 months), following two-step commands (24 months), and following three-step commands (age three to five). We also need to consider a child’s visual com-

munication skills: what is the child’s eye contact like? Does the child imitate and initiate gesture games such as patty-cake and peek-a-boo (typically at around nine to 10 months), and does the child point to desired objects (12 months)?

### Patterns of speech and language delay and what they mean

Some children have isolated delay in the emergence of speech, affecting vocabulary size, length of utterance, and intelligibility, with normal receptive and visual language, and no problems

in other areas of development. This pattern is seen in children with *dysarthria*, *Developmental Language Disorder (DLD)*, and mild-moderate *hearing loss (HL)*.

Dysarthria is a severe motor impairment of the ability to move the jaws, lips and tongue, and is generally encountered within the context of cerebral palsy. Symptoms include grimacing, excess drooling, difficulty feeding and severe difficulty with speech production. Dysarthria is hard to miss; the biggest danger is that an unwitting observer may mistakenly assume that the child lacks comprehension skills just because he or she may be nonverbal.

# Normal Speech and Language **Milestones**

AGE	AUDITORY EXPRESSIVE	AUDITORY RECEPTIVE	VISUAL
1 mo	Cooing	Alerts to voice	Recognizes parents' faces
2 mo		Turns to voice	
3 mo	Vocalizes back to parents		
4 – 6 mo	Babbles – single syllables (ba, da, goo, etc.) Laughs Blows bubbles	Turns to other sounds	
7 mo	Babbles – strings of syllables (lalala, etc.); Uses “mama” and “dada” but not always specifically	Understands “No”; Recognizes own name; Follows 1-step command with parental gesture	Imitates gesture games
8 mo			
9 mo			
10 mo	Uses “mama” / “dada” as labels for the correct parent		Upraised arms to signify desire to be picked up
12 mo	First word other than mama, dada	Follows one 1-step command without gesture	Initiates gesture games Points to desired objects
14 – 18 mo	Single-word vocabulary increases	Follows several 1-step commands; points to body parts	
24 mo	50+ single words; 2-word phrases	Follows 2-step commands	
36 mo	Sentences		Finger-counting

DLD is a catch-all term that encompasses children with isolated delay in the development of language, unaccompanied by any other disabling condition. Children with DLD typically present with delayed emergence of speech, and/or unclear speech. Receptive and visual language skills are generally intact. Speech in DLD typically improves with therapy and maturation. Often, however, the child who experienced delayed speech due

to DLD as a preschooler will show signs of a language-based learning disability in school, and/or problems with auditory processing (difficulty following speech in the presence of background noise, for example).

Children with HL need to have the underlying cause of the hearing impairment addressed – most often, recurrent ear infection, but occasionally some type of congenital abnormality giving

rise to permanent, partial HL. Those with permanent, severe HL will present with receptive as well as expressive language delay, but visual language skills (eye gaze, gesture games, index finger pointing) will be intact. Hearing loss (even severe HL) can be virtually impossible to tell just based on one’s subjective impression of how well a child seems to hear; evaluation by a properly trained audiologist is essential.

Many children with “delayed speech” actually have delayed language – despite the parents’ claim that the child “understands everything we tell him.” Often, the child’s understanding is based on the fact that the parents have compensated for the child, by breaking everything down into a series of one-step commands. The ability to follow one one-step command is a 12-month-old skill; following an infinite number of one-step commands is no better

than an 18-month-old skill. Delayed expressive and receptive language, plus delayed visual language (index finger pointing) is often a clue to the presence of *global developmental delay*. To assess this, one looks at the child's development in non-language areas. For example, at what age did the child master the use of a spoon (tool-use is typically around 12 months), or other self-care skills?

Finally, come children whose language is "off the track" or "atypical." Children with atypical development may have speech delay, or they may speak at the normal age, but their speech lacks communicative intent (reciting the alphabet or counting incessantly from one to 20, but unable to carry on a simple conversation, for example). This is the pattern seen in children with Autistic Spectrum Disorder (ASD).

early child development specialist – either a speech-language pathologist, developmental pediatrician, or other suitably trained professional – as well as obtaining an audiologic evaluation, no matter how well the child seems to hear. Treatment will depend on the exact nature of the problem, and can range from speech therapy focusing on articulation (in the case of a child with DLD) to a comprehensive program including intensive behavioural intervention (in a child with Autistic Spectrum Disorder). Long-term outcome will likewise depend on the exact nature of the cause of the child's original delay. Parents should take heart from the knowledge that early speech and language delays do not necessarily imply a long-term problem, and should act promptly, secure in the knowledge that early intervention offers the best hope for a happy, long-term outcome. ■

## “Wait and see” is almost never the appropriate response when confronted by concerns about speech or language delay.

Receptive language and visual language are also delayed or atypical; the child with ASD may “act deaf” even though hearing is normal, usually has inconsistent eye contact, and fail to use index finger pointing. Atypical behaviours are also seen in other domains, including physical mannerisms (hand-flapping, spinning), social isolation, repetitious play behaviours, and unusual hypo- or hypersensitivity to physical stimuli (light, sound, touch, taste, pressure, pain, smell).

### What to do if you think your child has a language delay

“Wait and see” is almost never the appropriate response when confronted by concerns about speech or language delay. The best course of action usually is to have the child evaluated by an

**James Coplan, MD**, is one of only a few physicians in the world who has earned specialty certification in Pediatrics, Developmental-Behavioural Pediatrics, and Neurodevelopmental Disabilities. He is the founder of Neurodevelopmental Pediatrics of the Main Line ([www.NDPeds.com](http://www.NDPeds.com)) and the author of *Making Sense of Autistic Spectrum Disorders – Create the brightest future for your child with the best treatment options* (Bantam-Dell, 2010). Dr. Coplan may be reached at [www.DrCoplan.com](http://www.DrCoplan.com)



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# imprints

A tribute to individuals and organizations that are making a mark in the exceptional community

**You might say Montrealer Karen Dubrofsky is a foodie of sorts, her passion for fine foods and cooking stemming as far back as age 10, when she began cooking dinners for her parents and two siblings.** But it wasn't until 2007 that the wife and mother of three decided to put her culinary acumen to wonderful use – by launching two cookbooks in the name of charity.

Karen was diagnosed at 23 with Eosynophilia Fasciatis, a rare autoimmune disease. She remained ill and dependent on various medications for seven years. During that period, Karen educated herself about the value of health and the importance of proper nutrition. Within two months of transforming her diet and eating habits, Karen was able to eliminate all medications and successfully overcame her disease. Inspired by her “life-changing” experience, Karen resolved to pay her good fortune forward and raise funds for health-related causes.

Following a successful campaign of events between 2003 and 2005 in which Karen and a friend garnered \$500,000 for the Centre for Colon and Rectal Surgery at the McGill University Health Centre (MUHC), Karen decided “to do something different”. In 2007, she launched *Montreal Cooks*, a collection of recipes from some of Montreal's premium chefs. It sold over 15,000 copies in both English and French, and gleaned \$700,000 in support of Women's Oncology equipment at the MUHC.

Not one to rest on her laurels, Karen set her sights on the creation of a second cookbook – this one to raise money for families affected by autism. *Cooking with Canada's Best* is a compilation of over 90 recipes from some of Canada's finest chefs from coast to coast. Although not personally affected by autism, Karen is full of admiration for the tenacity of those touched by the condition on a daily basis.



Karen Dubrofsky

**“When you speak to parents of children with autism, you understand how special these people are. If I can provide money that will help a child, then there is no explanation needed as to why I need to do this.”**

One hundred percent of the proceeds of *Cooking with Canada's Best* will go toward autism research, programs and services provided by organizations such as the Miriam Foundation, a non-profit foundation dedicated to enriching the lives of children, adults and seniors with Autism Spectrum Disorders and other intellectual disabilities.

Karen is presently working on a vegan-style cookbook to benefit Alzheimer's research and services. It's slated for release next fall.

*Know a person or organization worthy of national recognition? Send your nomination to [imprints@exceptionalfamily.ca](mailto:imprints@exceptionalfamily.ca)*

For more information about *Cooking with Canada's Best*, call 514-345-1300.



# Sure I can

A column dedicated to *living & succeeding with a disability*  
by Michael Lifshitz



PHOTO: JULIAN HABER

*In the spirit of the holidays, I was inspired to generate a wish list for the coming year. Rather than addressing Santa, however, mine is dedicated to the government and institutional bureaucrats who run our Home and Native Land...*

## All I want for Christmas:

### Eight “gifts” that would make life easier for exceptional people

#### 1 Invest in the children.

Among exceptional children’s greatest challenges, is the federal and provincial governments’ perception of people with special needs as liabilities rather than assets. This “expense mentality” maintains that there are insufficient funds to invest in more diagnosticians, therapies and early intervention treatment centres.

It has long been known, however, that the earlier a child is diagnosed with a condition and treated, the greater his or her chances are of benefiting from remediation. A higher-functioning child may ultimately be able to go to school or work, pay taxes and be a contributing member of society, rather than a future financial “burden” requiring full-time support. In order for exceptional children to be able to reach their full potential, they require government assistance in the present.

#### 2 Reduce red tape and wait times for services and support.

In 2003, I learned that I would need to use an electric wheelchair to ease a strain on my hips.<sup>1</sup> Given the wheelchair’s \$5000-plus price-tag, I was naturally grateful for government funding that would offset its cost. However, I had to wait six months for the government to review my health forms and documentation before finally subsidizing the wheelchair, and another six for funding approval to adapt a van to accommodate it (the adaptations cost roughly \$30,000). During that six-month period, my hips suffered increased wear-and-tear, contributing to a greater chance that I could be immobile. My immobility would mean I would discontinue working, and no longer be a contributing member of society.

The provision of therapeutic services and support could largely be facilitated by a significant reduction in the bureaucracy and paperwork involved in obtaining services.

#### 3 Point us in the right direction.

Once a child obtains a formal diagnosis, a challenge for many exceptional parents then becomes ascertaining where to turn for help. Resources, be they support groups, caregivers, or funding, are often poorly publicized. I was 12 before my parents learned that the War Amps of Canada had a Child Amputee Program that subsidizes the costs of prosthetics and related medical treatments not covered by provincial governments. Given that I had an artificial leg since I was 18 months old, it’s unfortunate that my parents were not apprised of this

1 As avid Exceptional Family readers will remember, I was born with a condition called Multiple Congenital Musculoskeletal Abnormalities. As a result, part of my bone structure was not properly formed and I have had my hips and right knee surgically constructed, have an artificial leg, walk with a cane and use an electric wheelchair for longer distances.



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# Sure I can

resource earlier, by the many professionals involved in my care.

Today, even with the Internet at our disposal, information presented online is overwhelming, and often incomplete and unreliable. It is a mistake for professionals to assume that people touched by disability are able to find resources on their own. Exceptional families need guidance and support to pinpoint appropriate interventions and services.

## 4 Facilitate our integration.

To the extent possible, children with special needs should be encouraged to attend mainstream schools and interact with “typical” peers. In addition to minimizing exceptional children’s isolation and marginalization, classroom integration also sensitizes “typical” children to the needs and challenges of people with special needs, while underscoring their strengths and capabilities.

Given that the success of a school’s integration program is largely contingent on the support systems in place, schools should be prepared with appropriate funding, support staff, and Special Education teachers to accommodate exceptional students.

Integration of exceptional people must also extend to the workplace; individuals with disabilities should be accorded the same opportunities for employment and career advancement as everyone else.

## 5 Increase accessible transportation.

As children mature into young adults, their ability to function independently in society becomes of greater concern and significance. A common problem with adapted transport in many provinces is that it is often unreliable and must be scheduled in advance. Given that many subway systems and

buses are not yet fully equipped to accommodate exceptional people, we must often resort to taking taxis which can become quite expensive.

Rather than relying on buses and subways (in stations lacking elevators), a more effective solution might be to increase the fleet of adapted taxis and enable exceptional users to ride them at rates subsidized by the transportation authority.

## 6 Enforce stricter building codes.

I’m often amazed by the degree to which Canadian building codes are lenient. In Quebec, for example, a building is not required to be equipped with automatic doors for wheelchair users. The door simply needs to be wide enough for a person in a wheelchair to navigate through. In e-mails to local politicians, I have offered to lend them my wheelchair

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and allow them the opportunity to try opening a door with one hand while seated and steering the wheelchair through with the other, but so far...no takers. Making our buildings more accessible will also benefit the aging members of our population.

## 7 Consult us – the people who need the accommodations.

I often look at an “accommodation” for people with disabilities and wonder who designed it. When I was in college, one of the campus buildings was equipped with ramps, but they were too steep for wheelchair users (and anyone else with mobility impairment, for that matter) to use. The college ought to have solicited a person with a disability to assess the configuration, and ensure that it was actually useable. Who better to say what is needed than someone who is living with the challenge?

## 8 Recognize us as “Differently-abled”.

I’m generally not a big fan of political correctness. However, when I speak publicly in the context of a sensitization program, I often employ the term “differently-abled” because I believe it holds tremendous meaning. People with disabilities just do things differently – be it walking differently, communicating differently or learning differently. And if society can begin to realize and accept this fact, then perhaps disabilities would cease being an issue, and exceptional people would be accorded the value we deserve. ■

**Michael Lifshitz, CA, MBA**, works in accounting at McGill University. He is also a motivational speaker and comedian. To learn more about Michael’s endeavours, visit [www.michaellifshitz.com](http://www.michaellifshitz.com).

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## Strategies for other teens with learning differences

by NATHAN WEISSLER

I am 17 years old and a high school junior. When I was four, I was diagnosed with Asperger syndrome (AS), an autistic spectrum disorder. Characteristics of AS<sup>1</sup> include mild to severe impairments in social interaction (translation: our social skills can be awkward at times), and the development of restricted, repetitive patterns of behaviour and interests (as evidenced in my own life by an early interest in numbers).

Among the many issues I have had to deal with over the years, is that of my learning style – how I learn best. My parents and I knew early on that I would need specific accommodations

in school, which were articulated and implemented via an “Individualized Education Plan”, or “IEP.” My experience in various Special Education programs since I was three has given me a greater understanding of, and appreciation for, people’s vastly diverse learning styles and ways of absorbing and retaining information.

I am largely a kinesthetic or tactile learner. Physically moving around and touching and feeling objects such as computer keyboards, for example, greatly stimulate and enhance my learning. Over the years, I have devised various strategies to help improve my ability to learn even further – techniques that may benefit other teens with learning differences as well:

**!** Putting assignments, facts, equations and concepts in a song and/or humming to myself has been especially helpful for me in classes where I have difficulty understanding the material. It helps me to relate to the material in a more relaxed way. For instance, if one had difficulty in an American History class and was learning about the election of Abraham Lincoln in 1860, he or she could sing something like: “In 1860, Abraham Lincoln was elected President, followed by secession and a civil war.” Personally, math is my most challenging academic course, and it is often helpful for me to compose a song in math class.

I recognize, of course, that it may be difficult to put one’s lesson into song

<sup>1</sup> Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition.

in a classroom where peers are trying to learn as well, as the singing may disturb them. In such case, one could always write a song on a piece of paper and sing it later. I certainly feel that's better than nothing!

My use of singing to calm myself is not confined to the classroom; occasionally, I find myself singing at home, in supermarkets, or when walking down the halls at school. Half the time it seems I'm totally unaware of it! A teacher

it was unfair that I was allowed to be mobile while they were not.

I think a reasonable compromise would be for a teacher to say, "We'll give it a try – letting you pace around. But if it becomes too distracting and detracts from the learning, I'll have to ask you to sit down. Perhaps you could step outside, study your notes and pace for five minutes once during each class if you feel a real need to do so." This would be the perfect balance in my

**SOMETIMES THE SOCIAL ATMOSPHERE OF ANY CLASS, LARGE OR SMALL, IS CHALLENGING, AND I BENEFIT FROM AUTONOMOUS, QUIET STUDY TIME.**

once asked me in a friendly manner, "What song do you have to sing today?" You always have songs, Nathan. What do you mean you don't have a song today?"

So while my coping strategy has proven an annoyance to some at times, others view it as an attribute.

**2 Walking around a room, i.e. pacing** has helped me as a kinesthetic learner. Some teachers have been more tolerant of this activity in the classroom over others; occasionally I have been asked to stop pacing partly because my behaviour was distracting, but also because I think my teachers didn't want my peers to think

opinion; conveying to the student that he or she must consider others' feelings and needs, but also recognizing the student's needs.

**3 Typing on a laptop or computer** has helped me to focus as well. I almost always type my assignments in school. Due to my hand-eye coordination difficulties, handwriting is challenging for me and mine is not very neat! But I also love the feeling of a keyboard. It makes me feel calmer and more relaxed. During my sophomore year, whenever my computer was broken, my English teacher would always let me use the computer in her classroom.

On the other hand, I am known for typing very loudly so at times teachers and/or peers have asked me to quiet down. Occasionally, I get so absorbed in what I'm doing, that I become oblivious to the effect of my typing on my peers. Still, I always try to pay close attention to ensure that I'm not disturbing others, and I will leave the classroom to work on another computer if need be.

**4 Independent work and study** has helped me greatly. Sometimes the social atmosphere of any class, large or small, is challenging, and I benefit from autonomous, quiet study time during the school day. Last year, instead of being part of a study hall or "Study Skills" class, as my school calls it, I was permitted to work independently in the library. I often find that my AS-related traits cause me to need more quiet time than others. The challenge in school has been to reconcile this need with school requirements – something I have been able to do wonderfully, as my teachers and case manager are very supportive.

In sum, I believe that learning may take any form, as long as the material is being absorbed and the student is benefiting. Regardless of the particular styles or techniques applied, if someone learns best while jumping on a trampoline, for example, teachers should seriously consider accommodating that particular method, if possible. As I prepare for college and then the adult work world, I am hopeful that I will be able to strike the same kind of balance in those environments as I have in high school. I sincerely hope that other teenagers my age share this optimism about their own lives and futures. ■

*Veeta Engel, M.S.W., M.F.T.*

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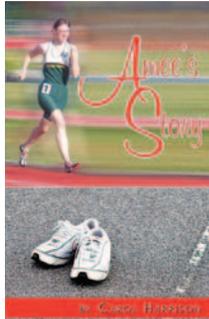
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# & Classics

A review of sensitizing books that center on *exceptional* issues

## Amee's Story

By Carol Harrison  
Guardian Books, 2010  
207 pages, \$15.00



In this festive period where faith and religion are central to many families, Carol Harrison's *Amee's Story* may be the perfect holiday read. Harrison is Amee's mother, and with purpose, conviction and unyielding optimism, she chronicles her now adult daughter's exceptional life from birth to 18 – a life marked by frequent bouts of illness, hospitalizations and significant physical, developmental and learning challenges stemming from diagnoses of microcephaly, epilepsy, cerebral palsy and hemaplegia.

While the Harrison family is forever altered following Amee's birth, Harrison emphasizes the positive in Amee's many successes and ensures that Amee's potential is defined by her abilities; not by doctors, some of whom give Amee a very grim prognosis, nor by teachers, who callously ignore her limitations and push her beyond her capabilities, nor by peers, who purposely exclude her because of her differences, nor by Amee herself, who at times is incredibly discouraged and frustrated by her challenges. Harrison's resolve to help Amee achieve her full potential shines in her daughter's rise from comatose baby fighting for her life in the NICU, to a young woman

*In many ways, my young adult daughter is still like a little girl. She needs supervision although she is able to stay home for a few hours at a time. Reminding her to drink and eat remains an everyday occurrence, since her brain still does not tell her she is hungry or thirsty. Routines are still required.*

*Any variation needs to be worked through in advance if possible. There are days when I wish she could do a little more. That's when I must stop and remember how far she has come.*

- Amee's Story

whose achievements – including graduating from high school and earning multiple awards as a track runner with Special Olympics – surpass everyone's expectations.

Amidst the highs and lows, life goes on in the Harrison home and family milestones are celebrated. Relatives graduate from high school and siblings marry and start families of their own. And through it all, Amee has to come to terms with the fact that it will take her significantly longer to reach some of the very same signposts, while she may never achieve others at all. Harrison also mourns this reality: "I grieved the milestones that were delayed, waiting in hope for them to happen, and the milestones, like getting a driver's license or living on her own, that never came to be."

Harrison is a devout Christian, something she makes palpably clear throughout her book. References to God, prayer, faith and miracles abound, as Harrison credits Amee's survival and subsequent flourishing to a higher power. And though it is published by a company that largely issues Christian-themed material, *Amee's Story* is far from a proselytizing tool.

Regardless of religious conviction, all readers will come away with a greater faith in humanity. It is a humanity exemplified by a mother's unconditional love and a daughter's unwavering courage.

The book's greatest flaw is perhaps its cover image; the colours and layout being somewhat reminiscent of the 1970s. In the case of *Amee's*

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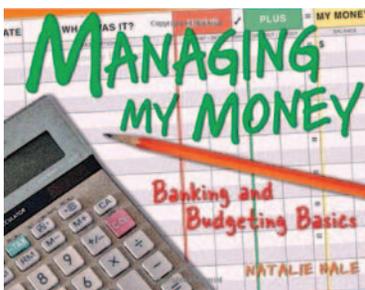
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Story, never was the old adage “Don’t judge a book by its cover” more applicable. ■

## Managing My Money: Banking and Budgeting Basics

By Natalie Hale  
Woodbine House, 2010  
175 pages, \$43.95



by LAUREN SILVER

Although geared for youth and adults with cognitive challenges, Natalie Hale’s *Managing My Money* is a wonderful teaching tool to equip all adolescents with the practical skills to manage their personal finances independently.

Presented in textbook format, the book covers three main headings: Keeping Records, Budgeting, and

Managing a Checking Account. Each topic is introduced and reinforced via short lessons that gradually build upon one another. Practice problems following each lesson help readers to generalize acquired knowledge to real-life

taught to think critically and concretely about money as something that can enter or leave their wallets.

Large, straightforward text and vibrant graphics enhance each concept, and the pages are free

*Let’s say you buy a shirt at a store. You write a check for \$25 even though you only have \$10 in your bank account. The store sends your check to the bank, as it usually does. BUT... Then the bank “bounces” it back to the store and marks it: INSUFFICIENT FUNDS!!! This is bad news. “Insufficient Funds” means “not enough money in the bank.” So the store owner calls YOU and demands that you pay for the shirt. The owner tells you more bad news: because you bounced a check, the store will **also** fine you.*

- *Managing My Money: Banking and Budgeting Basics*

situations. For instance, in the section on keeping records, readers are instructed to think of money spent versus money earned in either “plus” or “minus” terms. “Last night you went to the movies; your ticket was \$8. Plus or minus?” or, “You just found \$5 in your room that you had lost. Is that a minus?” are just two examples of how readers are

of clutter and distractions. A colour-coding system helps facilitate readers’ understanding of the concepts; red is equated with “minus”, for example, and green represents “plus”. In addition to the numerous blank sample forms within, *Managing My Money* includes a companion CD loaded with additional forms for practicing budgeting and check-balancing.

In order to facilitate the incorporation of *Managing My Money* into special needs classrooms and educational curricula, Hale includes teaching plans for educators on left pages throughout, while right-hand pages are intended for students.

Although certain topics (such as checking accounts) in *Managing My Money* may not apply to everyone, knowing how to keep track of incoming and outgoing finances, the foundational lesson taught in this book, is a skill for life – one which will serve to provide readers with independence and a sense of responsibility as they draw upon the book’s lessons in their daily transactions. ■



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# Meet the Blogging Mamas

by AVIVA ENGEL

Exceptional moms are taking the Internet by storm

They stay up late into the night and rise at the crack of dawn, capitalizing on their children's sleep schedules. They regularly chat in netspeak, employing words like "blogosphere", "blook" and "netiquette." They refer to their offspring in such shorthand posts as DS (Darling Son) and DD (Darling Daughter). They accord tremendous value to their moments in front of the computer, viewing them as periods of "me-time" – when they can relax and unwind after a busy, sometimes stressful day. Some even consider the pastime therapeutic. They take their passion extremely seriously, attending such North American conferences as BlogHer, Blissdom, Blogalicious, The Type-A Mom, and Mom 2.0. They've parlayed their social-media savvy into a movement of dedicated followers with similar issues and experiences. They're exceptional moms who blog, and they're taking the Internet by storm.

We searched the blogosphere high and low (actually, all it took was a quick Google search), and in a tribute to EBMs (Exceptional Blogging Mamas) the world over, are delighted to showcase four blogs worth checking out:

# The Mabelhood

[www.mabelhood.com/JulieCole](http://www.mabelhood.com/JulieCole)

**Launched:** 2007

**Creator:** Julie Cole, mom of Maginnis, 10, who has ASD (Autism Spectrum Disorder), Posy, 9, Spencer, 7, Jessamy, 5, Clancy, 3, and Finian, 16 months

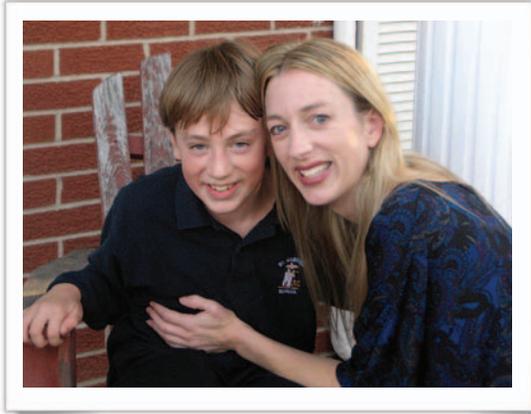
**Day job (besides mothering):** Co-founding vice-president of Mabel's Labels Inc., an online label company

**Motivation:** "Many bloggers feel that blogging gives them a voice. As an exceptional parent it is even more powerful – it allows you to advocate, educate, and dispel myths surrounding disabilities. For many parents who spend a lot of time in hospital with their children, it gives them a connection to the outside world while also providing a creative outlet. Blogging provides me with a forum to celebrate our achievements [as a family] and share our challenges. It connects parents facing similar issues, giving us a supportive community."

**Topics covered:** Parenting a child with autism; balancing everything in her life, amidst running a business and raising a large family

**Features:** Family pictures

**Updates:** Weekly



*"I love writing about our journey with autism and about the adventures of being a 'Mama of Many'. I have been honoured with award-recognition within the blogging community and thrilled to have guest-posted on some fantastic sites."*

# Love That Max

<http://lovethatmax.blogspot.com>

**Launched:** 2008

**Creator:** Ellen Seidman, mom of Max, 7, who has cerebral palsy due to a stroke at birth, and Sabrina, 5

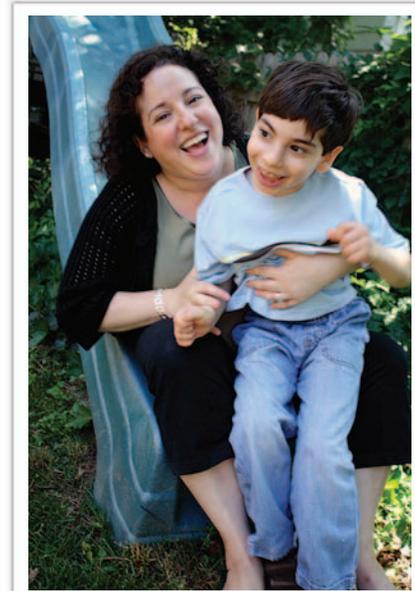
**Day job (besides mothering):** Freelance magazine editor and writer, currently working at Redbook magazine. Also blogs for 5 Minutes for Special Needs (<http://5minutesforspecialneeds.com>) and Hopeful Parents (<http://hopefulparents.org>)

**Motivation:** "After Max was born, I went through the toughest year of my life. There weren't a lot of blogs for parents of [exceptional] kids back then, and I felt so alone with my concerns and grief. By the time Max was 5, I was in such a better place; I started blogging primarily to inspire other mothers of young kids with challenges. I also thought it would be cathartic. And fun, too!"

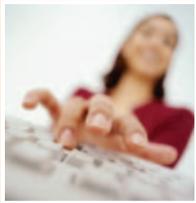
**Topics covered:** Parenting an exceptional child; parenting in general; her life in general, including her husband; fun lists (i.e. "Top 20 Reasons Moms of Kids with Special Needs Rock" and "The Special Needs Parent To-Do List"); Q&A's with experts and book authors; information on helpful products

**Features:** Family pictures; videos; giveaways

**Updates:** Daily during the week and often on weekends



*"It's been [everything I thought it would be] and more. My blog has become a thriving community for parents of kids with special needs, a place for all of us to share stories, struggles, confessions, and lots of laughs."*



## Interested to start a blog of your own?

Here are some tips from Julie, Ellen, Natalie and Chantel:

- 1.** Getting started always seems to be the biggest hurdle, and it need not be! You can set up a blog in a few minutes – simply Google how to do it. Then get writing! If you are really unsure of how or where to start, reach out to a blogger you admire and get his or her advice.
- 2.** When selecting a blog publishing application, WordPress gives you more options than others.
- 3.** If writing about your child, always respect his or her privacy. If your child has an issue which is particularly sensitive or potentially embarrassing, perhaps it should not be shared. “Many of us are proud of our children and how they face their challenges – that is okay,” says Natalie. “However, it is their disability not ours, so we need to be mindful of respecting their confidentiality.”
- 4. Don't be afraid to write about how you really feel.**

# All This and More – Journey of the 6packmom <http://the6packmom.wordpress.com>

**Launched:** 2010

**Creator:** Chantel Kowdrysh, mom of Joshua, 11, who has Asperger syndrome and ADHD, and Zachary, 5, who also has Asperger's, Marie, 12, Sebastian, 8, Arielle, 7, and Ryley, 4, and is expecting twins in February



*"I find writing to be very relaxing and therapeutic. It's a great outlet that allows you to express your true feelings - and let's face it, when you are a parent of a child with a disability you need to have something that you can do for yourself that helps you to deal with the everyday challenges you face."*

**Day job (besides mothering):** Freelance writer for various parenting magazines and websites, including Mississauga Kids and The Cute Kid; currently writing a book that's an extension of the material she covers on her blog

**Motivation:** “[Blogging is] an amazing opportunity for women to let their voices be heard. I find it to be a great way to meet other parents who have children with disabilities and to offer my thoughts on various topics.”

**Topics covered:** The daily adventures of her large family; life with a husband who is only home every four months (her husband is the CEO of a company based outside of her province); the challenges of raising two boys with special needs; her boys' struggles and successes; parenting tips

**Features:** Family pictures

**Updates:** Once a week, sometimes more frequently

# My Yellow Apple: Journeys in Parenting Asperger's Syndrome

<http://myyellowapple.blogspot.com>

"I have found that the process of writing helps me gain perspective. Something magical happens when I begin a new post. Usually an idea or issue is rattling around in my head, but once I begin to type, I find the clarity I need... Blogging has entered me into a wonderful community I did not know existed. My followers offer me kind words, validation and good ideas. I value their opinions, because many of them find me as I have found them - searching online for people who have shared experiences."



**Launched:** 2009

**Creator:** Natalie Dalton, mom of Aiden, 6, who has Asperger syndrome, and Margaret, 2

**Day job (besides mothering):** Now on a career break to home-school her children, Natalie was formerly a Special Ed teacher

**Motivation:** "[One of my reasons] was that I wanted to be a voice of true autism awareness. I wanted to broaden people's ideas of what autism is. While I certainly highlight the beautiful parts of autism, I think that it is important for people to know what it truly looks and feels like within a family context."

My [blog] is a way for me to pull back the curtains and let people peek into our home [and see] how Asperger's has affected how we do things, and how we experience things...I think we all benefit if the public is more knowledgeable and understanding of exceptionalities."

**Topics covered:** Family life; issues or experiences related to being an "autism family"; her viewpoints on topics related to autism; her feelings about parenting an exceptional child

**Features:** Family pictures

**Updates:** Three to four times per month



For more great tips on launching your own blog, check out Julie Cole's "What's the Deal with Blogging?" at [www.mabelhood.com/index.php/2010/08/whats-the-deal-with-blogging](http://www.mabelhood.com/index.php/2010/08/whats-the-deal-with-blogging)

## Blog On! Other noteworthy exceptional mom blogs

**My Little Ladybug** – about a baby undergoing the diagnostic process

**Three Chocolate Brownies** – about a boy with cerebral palsy

**Life with a Severely Disabled Child** – about a child who had a stroke

**Born Just Right** – about a girl who is missing part of her arm

**My Life with Gabriel** – about a boy with Down syndrome

**The Iron Chicken** – about a boy with Angelman syndrome



# In

# Focus

A column by psychologist  
Harriet Greenstone, Ph.D., OPQ

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## The Importance of Psychological Evaluations



PHOTO: JULIAN HABER

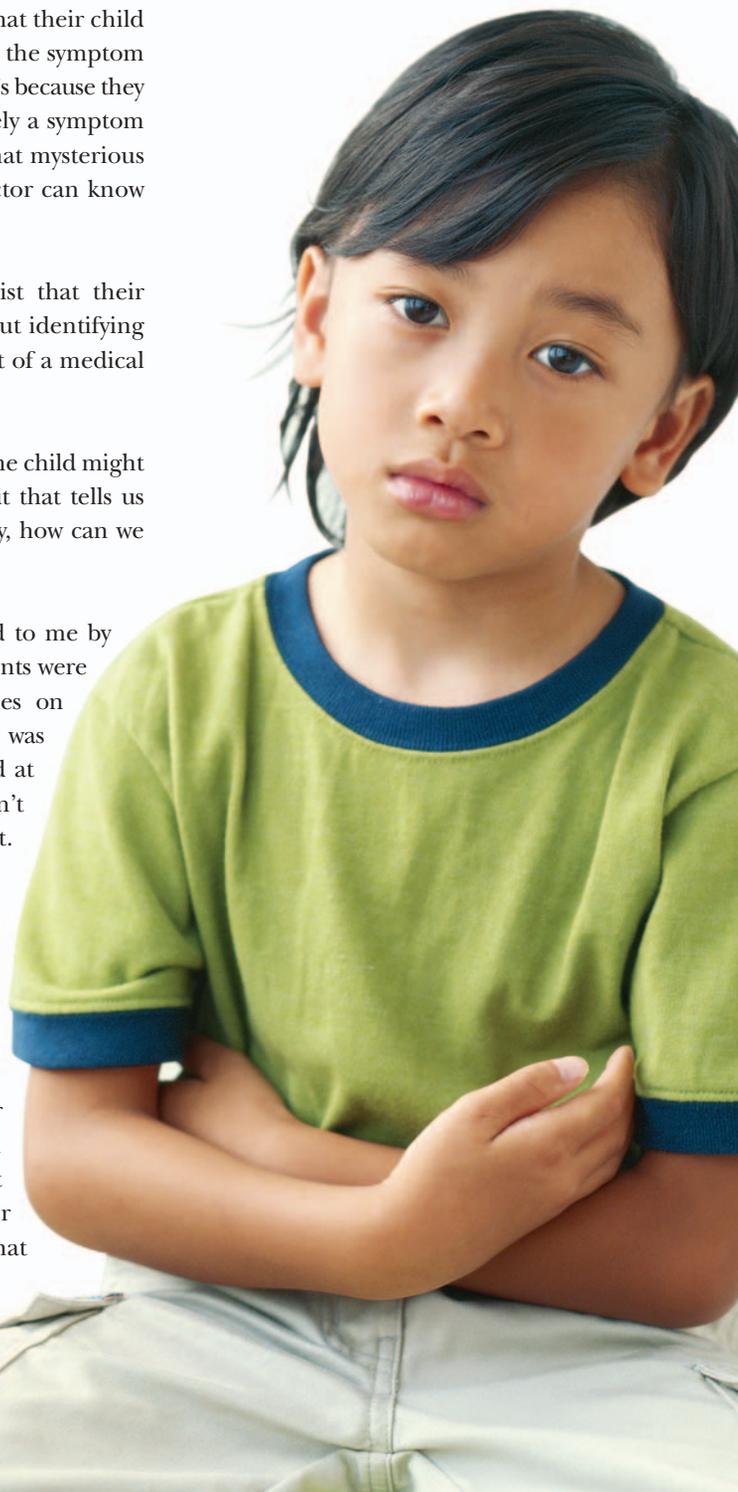
**V**ery few parents would tell a pediatrician that their child has a fever, and expect the doctor to treat the symptom without doing a medical examination. That's because they know the fever itself isn't the problem; it's merely a symptom that something is wrong with their child. And that mysterious "something" has to be identified before the doctor can know what to do about it.

But you may be surprised how often parents tell a psychologist that their child is having a problem, and expect that it can be treated without identifying its source via an evaluation – which is the psychologist's equivalent of a medical examination.

A child who is being oppositional or aggressive is a good example. The child might meet the diagnostic criteria for Oppositional Defiant Disorder, but that tells us nothing about *why* she is acting this way. And without knowing why, how can we help her?

Anxiety is another example. I remember a child who was referred to me by his doctor for treatment around his school-related anxiety. His parents were concerned because he would develop debilitating stomach aches on school days, and they (and his teachers) were mystified because he was a very bright young man, with a gifted vocabulary, who could read at a Grade 8 level when he was in Grade 3. I explained that I couldn't "make his anxiety go away" until I knew what was causing it. Fortunately, his parents agreed to have me conduct an evaluation.

While reviewing the evaluation's results, I noticed that he did very poorly on a test that requires visual concentration, visual scanning, visual-motor coordination, and processing speed. I told his mother these skills would be necessary for tasks like copying off a blackboard, for example. She gasped, and pulled a letter out of her purse. She had just received it from her son's teacher. It was the third letter relaying that he was the only one in class who could never finish copying off the board. Because he was so bright, everyone just assumed that he wasn't applying himself and was being lazy. Other test results revealed additional areas of weakness. It was obvious that despite his high level of intelligence, he was facing some significant challenges at school. Even worse, he was being blamed for them. And that would make almost anybody anxious!



## This description of five hypothetical elementary students

illustrates why we have to look beyond the “symptoms” to understand what’s really happening below the surface of a child’s behaviour. This necessitates an evaluation.

The first four students all share the same symptoms, but have different problems. The fifth student has the same problem as another, but “looks” completely different.

STUDENT	SYMPTOMS	LOOKED LIKE:	BUT EVALUATION REVEALED ...
SCOTT			<b>Auditory processing problems.</b> Scott tries to pay attention but it sounds like teachers are talking on fast-forward and he can’t keep up. So he often “zones out.”
KIRSTEN	<b>At school:</b> Constant fidgeting, squirming, and looking around the room.		<b>Memory problems.</b> Kirsten’s listening, but can’t retain what teachers say for very long. When they ask “What did I just say, Kirsten?”, she often looks like a deer in the headlights.
EMILY	Seem to be in a world of their own.  Easily distracted.  Answer most questions with a stunned, “What?”	<b>Attention problems</b>	<b>Sensory integration problems.</b> Emily can’t filter out the many sensations bombarding her at the same time (the cool draft from the open window, the smell of the teacher’s cologne, the itchy sweater tag on her neck, and Brandon’s incessant pencil-tapping at the next desk) to focus on the teacher’s words. Emily is paying too much attention, to everything!
BRANDON			<b>Attention problems.</b> Brandon has classic Attention Deficit Disorder. He can’t stop fidgeting and his mind keeps wandering off topic.
JACOB	<b>At school:</b> Focuses intently on the teacher and his work. Occasionally gets into schoolyard fights.  <b>At home:</b> Has recently begun having meltdowns, swearing at his parents, and being physically aggressive toward his younger brother.	<b>Aggressive problems / oppositional behaviours</b>	<b>Attention problems.</b> Jacob has ADD, like Brandon. He’s learned to fight it by “hyper-focusing” in class. But that takes a lot of effort. By the time he gets home, he’s too physically and emotionally drained to control himself. As soon as he lets his guard slip, his pent-up frustrations and anxiety erupt. His parents say, “He just can’t keep it together.”

Now that we had discovered *why* he was anxious, we could do something about it, in the form of classroom accommodations and activities designed to strengthen his areas of weakness. And the fact that his parents and teachers, and especially the boy himself, now understood that he wasn't being lazy, was a big help in reducing his anxiety.

Of course, challenges in the classroom are not the only sources of emotional or social difficulties. Some children might have deficits in executive function, for example. They may have great difficulty regulating their own emotions or dealing with transitions. Or, they might be unable to see another person's perspective (to put themselves in someone else's shoes), or be completely incapable of reading body-language, facial expressions, and tone of voice (a sort of "body-language dyslexia"), which can lead to very significant social problems.

There are myriad potential causes for social and emotional distress, just as there are a great many potential reactions to them. For example, a girl who can't regulate her emotions might have frequent meltdowns, or completely shut down. A boy with social problems might develop anxiety or depression, or be bullied, or become aggressive, or become the class clown in order to gain friends.



Understanding the causes of the behaviours will often enable us to give a name to the problem. But more importantly, it will give everyone an understanding of where the child is breaking down – and thus, often, where the “system” is breaking down.

That kind of insight was an important piece of the puzzle for an adolescent girl who was having frequent meltdowns at school. She would yell, swear, and slam doors. Obviously this was disruptive to the entire class and couldn't continue, but the school's response was to treat the “symptoms” by making her sign behaviour contracts, promis-

ing never to “act out” again. An evaluation subsequently revealed that she had severe problems with emotional regulation. She simply couldn't control her emotional outbursts, no matter how much she wanted to. So forcing her to promise not to have another meltdown was just setting her up for failure. Instead, understanding what would lead up to these emotional eruptions (in her case, classroom misunderstandings that were caused by her poor social skills) gave us a blueprint for intervention – social skills training, relaxation techniques, and anger-management for the girl, and accommodation by the school (allowing her to quietly leave the classroom and cool down whenever she felt a meltdown coming on).

Like medical examinations, psychological evaluations are part science (the testing) and part art (interpreting the results). We must first identify the underlying problems and understand how they relate to the behaviours or “symptoms” that caught everyone's attention, before we can even think about treatment.

And that should be the final goal – not merely to label the problem with a name, but to understand the source of the problem, so that we can help each child reach his or her full potential, academically and personally. ■

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**Dr. Harriet Greenstone** is a psychologist and the director of Centre MDC, a multidisciplinary care centre specializing in children, adolescent and adult evaluations and treatments. Harriet has done extensive clinical and research work in developmental and learning assessments. She teaches child development at Vanier College in Montreal.



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