

# Exceptional

CANADA'S RESOURCE  
MAGAZINE FOR PARENTS  
OF EXCEPTIONAL CHILDREN

Vol. 5 No. 2 • Winter 2009



# Family

Canada's **waiting children** with special needs

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ON THE COVER:  
Exceptional brothers  
Jaden, 7, and Devin,  
5, are in need of a  
permanent home.

Season's greetings  
and happy New Year

from our *Exceptional Family* to yours!



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# Exceptional Family

Vol. 5 No. 2 Winter 2009

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**Exceptional Family is an initiative  
of the Miriam Foundation.**



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ISSN 1715-4901

Legal deposit, Library and Archives Canada, 2005  
Legal deposit, Bibliothèque nationale du Québec, 2005

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## Helen Keller Made her Voice Heard – So Must We

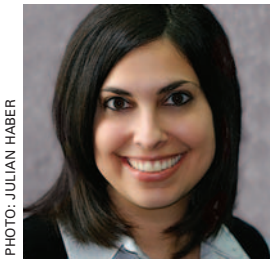


PHOTO: JULIAN HABER

The flippant incorporation of special needs references in pop song lyrics is hardly a new phenomenon; baby boomers might recall The Who's 1969 smash hit *Pinball Wizard* about a "deaf, dumb and blind kid" who "plays a mean pinball",

while Gen Xers are undoubtedly familiar with the Black Eyed Peas' 2003 single *Let's Get Retarded*, whose lyrics entreat "get stupid...get cuckoo...bob your head, like Epilepsy...come dumb now". Natasha Bedingfield's UK-chart-topper *These Words* followed in 2004, in which she employed Attention Deficit Disorder as an adjective to describe her frustration over writer's block ("I tried to focus my attention, but I feel so A-D-D).

One band, however, recently set a new low in the sensitivity category: 3OH!3, an American alternative electro-rock band, has come up with a vulgar way to portray Helen Keller. In *Don't Trust Me*, a downright crude song about a prostitute, the lyrics depict a woman being ordered to "shush girl, shut your lips, do the Helen Keller and talk with your hips." A dubious honour, if ever one was intended.

Some might question what the big deal is; after all, Keller died over 40 years ago. Surely 3OH!3 merely employed its artistic license and alluded to her for the sake of visual imagery! Besides, the laws of defamation only apply to those who are living.

The big deal is that it's precisely because Keller's no longer alive and able to stand up for herself that 3OH!3 felt safe enough to convert her name into a noun denoting submission, vulnerability and sexual promiscuity. Keller's definitive absence almost guarantees that neither lawsuits nor public outcries will ensue around the band's debasing and deplorable act. Now buried, it is Keller who's effectively been shushed.

Even more disconcerting is the song's overwhelming popularity among young people. According to the Recording Industry Association of America, the single has already hit double platinum, defined by the RIAA as two million copies shipped. The big deal rides on the tremendous power of music and pop culture to shape developing minds and influence youngsters' values and attitudes.

Before our children have the opportunity to learn about Helen Keller in school, or through literature, films and plays, they will already have been exposed to her via this song. And all that they will know about her – erroneously – is that she "talked with her hips." Not that she was a remarkable, determined and educated woman, who persevered in spite of her disability. Or that she was a prolific author, renowned lecturer, and women's and workers' rights activist. Or that she was the first person who was deaf and blind to earn a Bachelor of Arts degree, and actively fundraised for the American Foundation for the Blind. Or that her peers included the likes of Mark Twain and Alexander Graham Bell.

The responsibility falls on us – parents and educators – not only to tell our children about Keller's exemplary achievements and our disdain for this offensive song in particular, but also to convey our universal objection to *any* song in which disabilities and exceptional people are trivialized.

Helen Keller was far from submissive. In tribute to her heroism, we need to speak out too. Join me in voicing your disapproval of 3OH!3's lyrics by e-mailing the head of their management company, at Mike@KMGMT.com. Let's let the band know just how big a deal it is.

A handwritten signature in black ink that reads "Aviva".

**Aviva Engel**  
editor@exceptionalfamily.ca



*The Hutton family: parents Yvonne and Malcom (back row) with their children and grandchildren. Front row: four of the Hutton's adopted kids – twins Alex and Daniel, Ethan, and McKayla (flowers).*

# A Home for the Holidays - and Always

*A special exposé  
on Canada's  
waiting children  
with special needs*

by LINDSAY LAFRENIERE

The holidays are a time for opening presents under brightly lit trees, singing carols, attending religious ceremonies, eating extravagant meals and ice skating outdoors. But above all else, the holidays are a time to celebrate family.

Yet there are thousands of children across the country without a “forever” family; children who are waiting to be adopted. More than 30,000, in fact.<sup>1</sup> Of these children and youth between the ages of newborn to 17, thousands also have special needs, ranging from very mild to more severe. But perhaps their biggest needs take the form of their yearning to belong, especially during this time of year.

According to the Adoption Council of Canada (ACC), gathering domestic adoption numbers has always posed a challenge in large part due to the provincial mandates surrounding child welfare and the varying reporting mechanisms of the provinces and territories. While all children waiting for permanent homes are deemed to have “special needs” by virtue of having experienced the loss of their biological families, “the number of them with [diagnosed] special needs is a bit harder to find,” says Sarah Pederson, the ACC’s acting executive director. “The provinces tend not to break [special needs] down into such fine categories.”

<sup>1</sup> Specifically 30,717, according to information tabulated by the Dave Thomas Foundation for Adoption (Canada) from the fifth edition of the Child and Family Services Statistical Report, October 2007. Produced by F/P/T Directors of Child Welfare Committee, includes statistics through July 2004.

## Alberta: A leader in domestic adoption

The province of Alberta is considered exemplary in its proactive measures to find permanent families for children and youth in need. "Alberta uses aggressive recruitment techniques to find homes for their waiting children," says Pederson. "They have a provincial [recruitment] program and routinely use our national recruitment program, Canada's Waiting Children. The methods that they use are wonderful and have been very successful."

Alberta Children and Youth Services runs a successful adoption program that has placed exceptional children in loving families for more than three decades – children with learning challenges or disabilities like Down syndrome, Seizure Disorder, and global developmental delay. "In Alberta, we have approximately 160 to 200 children and youth available for adoption at any given time, all of whom have special needs," says Anne Scully, manager of Adoption and Permanency Services. The process of adopting a child begins with an application, in which applicants present information on themselves and their family and indicate which special needs they are willing and able to consider.

"The family has to minimally accept three different special needs: behavioural issues, learning disabilities or developmental delays" says Nadia Zubach, manager of Adoption Matching and Media Recruitment. "If a child has extensive medical needs, we would be looking for a family that lives near all the resources needed, such as in a big city where specialized medical services are more readily available. If [the applicants] are knowledgeable about the special needs that the child

has, there is a better chance that the adoption will be successful."

According to Scully, applicants must then undergo parent-preparation training, which consists of intensive sessions of approximately 24 hours in duration. Topics covered include attachment and behavioural issues, advocating for the child, special needs that the child may have, resources required and potential learning challenges.

A home study report is then completed and, once it is approved, the family is eligible to be matched with a child or youth. The children's caseworker participates in selecting an adoption match for the child

with the family during the adjustment process." On average, the adoption is finalized within one year after the child is placed in the home.

## Support programs

The Support for Permanency program was implemented by Alberta Children and Youth Services in 1990 and has been enhanced to meet the exceptional needs of adoptive children. Financial aid includes 100 percent of basic foster care maintenance rates, funding of up to \$70 per week to assist with a child's emotional or behavioural needs, and respite care of up to 576 hours per year, among other supports.

Applicants must present information on themselves and their family and indicate which special needs they are willing and able to consider.

through an electronic matching system. "Once matched, it takes approximately one month to place the child in the home," says Scully. "We ensure the necessary supports are in place before the child is placed with the family and the child's caseworker works together

Alberta's Family Support for Children with Disabilities program, which is unique in Canada, provides many additional services for families. These may include assistance with the costs of medical appointments and treatments, hospitalization, counselling, and childcare.


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## Harnessing the power of media

Alberta Children and Youth Services has used media extensively to the advantage of exceptional children waiting to be adopted. Prospective families may view profiles of eligible children and youth on the ministry's website. Children and Youth Services also work with CTV to produce the *Wednesday's Child* program. This 38-segment series airs during prime

time news and features children and youth who are waiting for permanent homes. Children 12 and older must provide consent for media recruitment, and in all instances foster parents, caseworkers and managers must also sign consent.

Approximately 70 per cent of the children and youth profiled on *Wednesday's Child* and our website are adopted.

“We’ve been working with CTV for well over 25 years,” says Zubach. “It’s

## The Hutton family

“Your birth children grow in your tummy, your adopted children grow in your heart.”

This is Yvonne Hutton's motto. She and her husband, Malcolm, have opened their home and their hearts to four adopted children with special needs, and are in the process of adopting a fifth.

Originally from England, the couple have two biological sons and two daughters, ranging in age from

20 to 33 years old. In 1994, they realized they wanted more children and initially chose to go the foster-parent route.

Three of the biological children lived at home at the time. Upon sharing their intentions with the rest of the family, Yvonne recalls that her son Mike, who was eight at the time, loved the idea that he would be getting new playmates. The older kids didn't take their parents seriously, and initially reacted with something like, “You're kidding, right? More kids?” Still, the four treated their new family members like siblings from the beginning.

Between 1998 and 2000, the Huttons fostered four children. Then, in 2000, they met three-day-old McKayla, whom they later adopted. Given that McKayla was affiliated with a First Nations Band, it was necessary to undertake a consultation process to secure her release for adoption. The family shared their joy when the Bands' support for McKayla's adoption was ultimately obtained. “The wait was well worth it!” says Hutton.

While waiting to finalize McKayla's adoption, the Huttons legally adopted three-year-old Ethan, now 10, through an international adoption from Haiti, in 2003. “International adoption was huge amounts of paperwork and you are very much in the dark on that route,” says Hutton. “Our other adoptions were through Alberta Children and Youth Services. We like the fact that you got all the information on the children, met with teachers and doctors and read all the reports. So you have a really good picture of the child and his or her past.”

They then adopted identical twin boys, Alex and Daniel, in 2007, and are now in the process of adopting



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Addison. The twins are six and Addison is five. All of the adopted children have a variety of challenges. “We have three children with FASD [Fetal Alcohol Spectrum Disorder], two with attachment disorder<sup>2</sup> and some developmental delays,” says Hutton. “All of them were or are severely speech-delayed and they see occupational therapists for gross and fine motor delays.”

The Huttons celebrate their children’s strengths and accommodate their special needs. The kids are enrolled in many activities such as tap dance, hip hop, swimming and gymnastics, to improve their motor skills. Yvonne does a lot of school-work with the children and a tutor comes in to help a few hours a week.

“We have learned over the years to change, because we are a ‘FASD family’,” says Hutton. “Children with FASD need lots of routine and structure, so we are very well organized. Everyone knows what is expected and what is coming next. It was easier for us to become a FASD family than to try to make my kids into non-FASD kids. That’s not going to work!”

Hutton encourages potential parents to fully educate themselves on adop-



Four of the Hutton’s adopted children: McKayla, 9, Alex, 6, Daniel, 6, and Ethan, 10.

tion and special needs, and urges people not to be afraid of adopting an exceptional child. “Please don’t let anyone put you off, especially when you hear [something like, ‘the prospective child] may have some FASD’. This is not as bad as you think,” she says.

“Mostly it’s the lack of knowledge that scares people away [from adopting]. These kids need a family. All they require is to be loved and to belong.

There is lots of information you can get from talking to other parents who have adopted, and visiting government websites [that touch upon] all types of special needs. Read, search, ask, talk, meet families and then ask yourself if you can open your heart and home to one of these very deserving children.”

As they do every year, the Huttons plan to spend the holidays together as a family. There will be a turkey dinner, plenty of opportunities to decorate, play games and watch movies, and time to sit by the fire and reflect on their blessings, says Hutton.

“I cannot imagine my life without my kids. The love and joy I get from them is indescribable.” ■

For more information on adopting a child in Canada, visit [www.canadaswaitingkids.ca](http://www.canadaswaitingkids.ca), and [www.adoption.ca](http://www.adoption.ca). For more information on adoption in Alberta and to view profiles featured on Wednesday’s Child, visit [www.child.alberta.ca](http://www.child.alberta.ca)

<sup>2</sup> Attachment disorder is a broad term intended to describe disorders of mood, behaviour, and social relationships arising from a failure to form normal attachments to primary caregivers in early childhood, resulting in problematic social expectations and behaviours. [http://en.wikipedia.org/wiki/Attachment\\_disorder](http://en.wikipedia.org/wiki/Attachment_disorder)



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# In Search of a “Forever” Family

A sampling of Canada’s waiting children with special needs



Devin, age 5, and Jaden, age 7

Jaden and Devin are delightful brothers who require a permanent home where they can remain together. These active boys play well with their peers and with each other. They are happy and sociable children who are a pleasure to be around.

Born in 2002, Jaden has blonde hair, blue eyes and a lean build. He is shy upon first meeting someone, but becomes animated once his comfort level increases. Jaden smiles easily and likes to talk. He does well in a school program that helps him to meet his individual needs. This patient little boy enjoys playing with toys and games requiring focus, and loves outdoor activities, including camping and barbecues.

Devin, born in 2004, has blonde hair, blue eyes and a lean build like his brother. Although shy at first, he is very likeable and sometimes mischievous! Devin benefits from the extra support of a specialized school program. He enjoys playing with toys and games and participating in music activities at school.

This sweet duo would benefit from energetic, patient and loving adoptive parents who are able to provide them with extra support and guidance in order to help them to meet their maximum potential. They would thrive in a home with or without other children.



Joe, age 13

An easy-going and gentle boy, Joe loves playing video games, camping outdoors, fishing and swimming, and has a keen interest in cars, insects, spiders, snakes and sharks.



Lorenda, age 12

A quiet and friendly child, Lorenda enjoys reading, baking, horses, swimming, movies, music, dancing and dolls.



Kayla, age 7

A loving and active girl, Kayla enjoys waterplay and toys of all kinds – particularly ones that make noise.



Johnathon, age 2

A sweet-natured and active toddler, Johnathon loves outdoor activities and play involving cars, trucks, and LEGO®. His favorite TV shows include Dora the Explorer and Sesame Street.

For additional information on the children featured here and others available for adoption, visit [www.adoptionAlberta.gov.ab.ca](http://www.adoptionAlberta.gov.ab.ca), or contact Alberta’s Adoption and Permanency Services at (780) 422-3040.



# Choose Your Advocate Wisely:

## TOP 4 TIPS

# to Get the Best for Your Child

by JENNIFER KRUMINS

**N**avigating the parenting role is tricky at the best of times. Finding your way with an exceptional child is even more demanding and difficult; it's a path that may not have been traveled by family and friends. Loneliness, disappointment, frustration and a sense of failure can make the journey even bumpier. Amidst the struggle of grappling with your emotions, it is sometimes difficult to think objectively and make sound decisions on your own. If you find yourself in this position, you may wish to consider hiring an advocate – a person qualified to help you pinpoint the best resources and solutions for your child and family.

An advocate is a single person who may or may not work in tandem with members of a child's multidisciplinary

team. Although some parents may feel perfectly confident to make decisions related to their child's special needs on their own, others prefer to be guided by a trained professional who knows "the ropes". An advocate may play some or all of the following roles:

- Assist you to find available support for your child
- Model relationship-building and problem-solving skills
- Listen to all parties in a genuine and nonjudgmental manner
- Clarify issues, suggest options and possible solutions
- Accompany you to meetings and appointments
- Speak on your or your child's behalf if you cannot speak for yourself due to language barriers, emotional upset or

lack of understanding

- Help you to make sense of documents such as psychological assessments
- Help you with documentation, written correspondence and phone calls
- Follow-up on decisions and actions taken

### Be discerning in your selection

Before choosing your guide, you must do some homework. There are many people who call themselves "advocates." As the child's primary caregiver, it is up to you to assess an individual's qualifications, and whether he or she is a good fit for your child and family. Take the time to research your options. The decision you make will not

During the interview process, listen and observe your candidate carefully. Red flags should wave wildly when promises of specific outcomes for your child are made.


only affect your child – it may also impact your relationships with school personnel, your spouse and other family members. An advocate who foments tension and

distrust between you and the school authority, for example, can do more harm than good for your family. The following tips may help you in your selection:

**1 An advocate should be knowledgeable about learning differences.** Credentials and experience in the field of special education bring a level of respect to the table. Educators will likely be more open to the opinions and suggestions of someone who is *qualified* to make them. The pursuit of ongoing professional development via conference attendance, keeping up-to-date on current policies and procedures, and maintaining a solid knowledge-base of local resources, service providers and community programs, are all signs that a potential candidate is qualified for the job.

**2 An advocate should be prepared to get know your child.** An effective advocate takes the time to read a child's assessments, educational and service plans and report cards, and spends significant time with both the child and family in order to understand exactly whom he or she is representing. An advocate should also observe your child in the context of his or her classroom, since a student's Individual Education Plan (IEP) can never adequately convey the full scope of supports he or she may receive daily. An effective advocate will ask questions and seek the whole story.


**3 An advocate will remain objective, even in highly emotional circumstances.** During the interview process, listen and observe your candidate carefully; does he or she talk as though you are going to battle, employing words that point fingers or call for vengeance? Red flags should wave wildly when an advocate sees only negatives in your child's education, or when promises of specific outcomes for your child are made. An advocate who speaks with an



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While an advocate may refer to people and resources that he or she may have worked with in the past, his or her personal history and experiences have no place in discussions. This is about *your* child and family.

**4 An advocate should be a facilitator, not a dictator.** The person you hire should have the interpersonal skills necessary to work collaboratively with others toward solutions. He or she should demonstrate respect, courtesy, consideration and open-mindedness. Each member of a team has a perspective on how to best

all have ideas that stem from their training or experience. A skilled advocate is able to listen to the ideas of each member of a multi-disciplinary team and draw on the strengths of each individual. Finally, while an advocate may or may not be affiliated with an attorney, it is critical to keep in mind that advocates are not lawyers and should not be giving legal advice. The advocate's purpose is to serve as a *facilitator* in the achievement of positive goals.

### The parent as primary decision-maker

Hiring an advocate does not detract from your role as primary decision-maker. An advocate's role is that of a guide. He or she may make sense of documents, technical language and educational jargon, or explain the requirements of special programs, attend meetings and ask clarifying questions. But as the child's parents, you make the decisions. Your child needs *you* to be in charge; your role is *long-term!* While the relationships between you and those working with your child can be challenging and emotionally-charged at times, you are ultimately all working toward the same objectives. With respectful dialogue and child-centered problem-solving, it *is* possible to work as a team. It is up to us adults to make it work for the sake of our children. ■

"I'll show them," attitude is going to be ineffective in getting everyone on board with his or her plan.

help a child; a principal, community agency representative, speech pathologist, teacher, and parent

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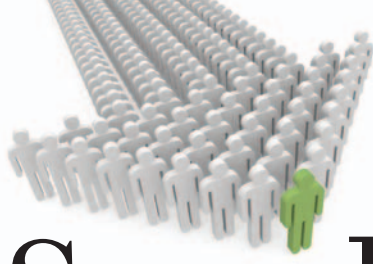
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**Jennifer Krumins** has 19 years of experience in special education and the regular classroom and currently teaches teens with autism and severe behaviour challenges. She is the author of numerous books. Contact Jennifer at [krumins@autismaspirations.com](mailto:krumins@autismaspirations.com) or visit [www.autismaspirations.com](http://www.autismaspirations.com).



# Sure I can

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

## Going the Distance to Prove That I Can



**W**hen I introduced this column in the spring of 2006, I had two main goals: first, to inspire parents of exceptional children by serving as an example of their future potential; and second, to educate the population at large about the ability of exceptional people to succeed at almost anything

they set their minds to. Based on reader feedback I've received over the years, it appears I've accomplished my first objective. Until last month, however, I never realized the lengths to which I would go to prove the latter point. I can now officially confirm that I'd go as far as 360 feet – the distance between myself and the ground when I recently repelled down the side of an office building in downtown Montreal as part of the 2009 Easter Seals Drop Zone.

Established in 1907, Easter Seals is an international organization dedicated to enhancing the quality of life, self-esteem and self-determination of Canadians with disabilities through various programs which it offers in conjunction with its provincial affiliates. The Drop Zone is an annual fundraiser held in St. John's, Halifax, Montreal, Winnipeg, Regina, Saskatoon, Calgary, Edmonton, Vancouver and Victoria, dedicated to supporting summer camp programs for exceptional children across the country. Each participant must raise a minimum of \$1,500 in sponsorships in exchange for the chance to repel down a building.

In Quebec, Easter Seals has joined with the Quebec Society for Disabled Children to raise money for its Camp Papillon, a sleep-away camp in Saint-Alphonse-Rodriguez, Quebec. According to executive director Ronald Davidson, Camp Papillon was founded in 1938 with the aim of providing exceptional people with an



**TOP:** Michael and Frederique Audette, a specialist in rope access techniques, gear up for the big drop.  
**RIGHT:** The dynamic duo take the plunge.

“environment where [they are] in control of what is going on” and “activities they thought they would never be able to do.” The camp also affords parents and caregivers “a chance to breathe and recharge their batteries so they can keep [their] children at home for as long as possible,” says Davidson, who estimates that camp participants have 80 different forms of disability.

I learned about the Drop Zone only three weeks before it was to take place, from Aliea Jamal, special events coordinator for the Quebec Society of Disabled Children, whom I met at a business networking event. In explaining the event to those present, Jamal relayed that people with disabilities had participated in the Drop Zone in the past. I decided if they could do it, I should be able to do it too. Not only would my participation set an example for others, I reasoned, it would also allow me to help others in need. I have always considered myself fortunate in that, while I have a disability, I am still able to live a full life. If I could contribute to a wonderful camp experience for an exceptional child, I felt I should.

I only wondered which would be the bigger challenge to overcome: my disability, or the fact that I'm afraid of heights. Knowing that the activity would be supervised by experienced professionals, however, I signed up that night and began my quest to raise the \$1,500. (I am proud to say that at the time of this writing, I had reached a total of \$2,000.)

As I went about fundraising, I was met with admiration, a degree of astonishment and some downright disbelief.

gloves) and met Frederique Audette, a trained specialist in rope access techniques who would accompany me down. In total, there would be six people supporting me both on the roof and waiting at street level. After a practice run from a training station about 15 feet off the ground, it was time for us to ascend to the roof. A little apprehensively, I rode my wheelchair up to the 25<sup>th</sup> floor and walked up two additional flights of stairs leading to the top of the building.

As I waited for my turn, I found myself surprisingly calm, until it came time to actually mount the ledge leading up to my big leap!

My mind raced with thoughts of are you !@#\$\$% nuts?! For a split second I entertained backing out.

I was encouraged, however, by the fact that most people were not shocked by my willingness to participate as a person with a disability, but rather by *anyone's* willingness to participate in such an activity – something I found oddly comforting.

When Drop Zone day came, I arrived at the site where I donned the appropriate rappelling gear (which consisted of a helmet, harness and

With the assistance of the professionals in charge, I was hoisted up a ladder to the ledge platform. As I stepped down, I was instructed to lean back. "Let yourself go and don't worry, the rope will hold you," I was told, as if those words were supposed to offer reassurance.

My mind raced with thoughts of *are you !@#\$\$% nuts?! For a split second I entertained backing out. But then*

I rationalized again that I was in professional hands and having a guy with a disability plunge to his death would probably look bad for business. More importantly, though, I had collected donations and made a commitment and I was going to see it through.

After getting my legs over the ledge and spending a couple of minutes dangling parallel to the wall, I managed to get both feet on the wall, drawing encouraging cheers from my assistants, which made me quite proud.

While I lost my footing roughly a quarter of the way down and needed Frederique's support, I still reached the bottom with an overwhelming feeling of accomplishment. Not only had I faced my fears, I had also fulfilled my pledge to help someone else share in the joy of going to camp. Easter Seals refers to Drop Zone participants as superheroes. Scaling down the office building that day, I certainly felt like one.

While my muscle soreness has since subsided, my sense of pride has not. I plan to do the Drop Zone again, only next time, in a manual wheelchair; I am told the experience will actually be far easier than rappelling with one "good" leg was.

Registration for the 2010 Drop Zone begins in January. Why not join me and be a superhero for one camper, and conquer your fears? I am sure you can. ■

For details about the Drop Zone Challenge, visit [www.thedropzone.ca](http://www.thedropzone.ca).

**Michael Lifshitz, CA, MBA**, is a consultant for Investors Group Financial Services Inc. in Montreal. Contact Michael at [sureican@exceptionalfamily.ca](mailto:sureican@exceptionalfamily.ca)

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# ABILITIES CHURCH:

## A Spiritual Model of Integration

by STEWART LAZARUS

Like most university students, 25-year-old Kenny Rojas is looking forward to the Christmas holidays. While the break from school and more time to spend with friends appeal to the York University radio/broadcasting student, Kenny is eagerly anticipating celebrating Christmas at Toronto's Abilities Church, Canada's first fully inclusive, inter-denominational church.

Kenny is excited to share one of his biggest passions with the church's growing congregation: his music. In addition to playing the drums in a band for over 12 years, Kenny has impressive DJ skills and loves to perform before a crowd. As someone with a visual impairment, however, it has not always been easy for Kenny to showcase his talents publicly. "In the past when I would ask to perform at other venues, people would be very nervous," Kenny explains, "They would think that because I am blind, getting up on stage would be too dangerous for me."

Last Spring, however, Kenny found the Abilities Church, a community that not only encouraged him to play before a large audience, but also embraced him as one of its own. Under the leadership of found-

ing pastor Jaime Castro, Abilities Church strives to fulfill its mission to "cultivate spiritual equality, empowerment and encouragement for all people" and to "give people with disabilities opportunities to participate in the worship and ministry."

"At Abilities, nobody focuses on me being blind; instead they focus on my music," says Kenny, who also often speaks publicly during the worshipping and shares his thoughts with the rest of the congregation. "[The church allows] people with disabilities to be at the forefront," he says, grateful for the added confidence he's acquired through his affiliation. "It has allowed me to be happy and proud to be blind."

### Realization of a dream

For Castro, 39, the opening of Abilities Church was a culmination of a lifelong commitment to change the way mainstream society thinks of people with special needs. At 18, Castro began working with exceptional people at Community Living Toronto, a support and resource agency for individuals with intellec-

tual disabilities. That experience, Castro notes, was incredibly moving, even life-changing. "I was blown away by participants' joy, positive outlook, and enthusiasm despite their disabilities. I realized that these people could inspire an incredible message of hope, strength, and faith," he says.

Following Community Living, Castro became president of the Mix Community Club, a nonprofit social organization that provides community entertainment inspired by people with disabilities. There, he organizes outreach events intended to bridge the gap between the exceptional and mainstream communities. One such celebration was held last summer at Toronto's Nathan Phillips Square. It drew over 1000 people, and garnered the support of politicians including



*Kenny Rojas performs during a worshipping service at Abilities Church.*



Prime Minister Stephen Harper and Ontario's Lieutenant Governor, David C. Onley.

Through his work at both Community Living and the Mix Community Club, Castro began to embrace the idea that people with challenges could and should be involved in all aspects of community life. He also felt that additional effort should be made to integrate exceptional people within the spiritual community. "Growing up in church, I never encountered anyone with disabilities. I wanted to change that," he says.

Integration is at the core of the Abilities Church mission. "This is not a disabled ministry but an inclusion ministry for the whole community. One of the goals of the church is to reach out to a congregation made up of 50% people with disabilities and 50% people without," Castro stresses, adding that worshippers without disabilities can learn valuable lessons from those with challenges, particularly when exceptional people ascend to the podium and speak from their hearts. Abilities Church is also unique in that it is open to worshippers of all religious denominations. "We as humans are all the same; we all share the same struggles. We have much more in common than what divides us."

Castro recalls the degree to which he himself was inspired at the church's recent grand opening celebration. "I was overcome with emotion; I couldn't help but tear up when recognizing how historic this church can become. Our congregants with disabilities break down socially-constructed barriers every day," he says, of the exceptional members, who also assist with fundraising, and the promotion of the Abilities message.



*Pastor Robert Gagnon*



*Pastor Jaime Castro with son Christian, 2, and Abilities Church usher Jordan Power.*

## Participation encouraged

Linda Dupuis, an Abilities Church congregant from the mainstream community, agrees. Dupuis attended the Church's opening services, which she summarizes as "an enlightening experience for people of all ages and backgrounds. The congregation got involved. It was a very interactive service and nobody was asked to be silent." According to Castro, exceptional people often get a cold reception at other churches because some tend to "vocalize their emotions quite loudly" and may have trouble sitting quietly. "These people are not disruptive, they are merely expressing their enthusiasm

which should be welcomed and encouraged," he says.

The balance between mainstream and exceptional congregants also exists among Abilities Church leaders. While Castro represents the community of people without disabilities, associate ministry pastor Robert Gagnon has cerebral palsy. Gagnon has been instrumental in leading the congregation and actively promoting the church's messages to potential members. While he has never personally experienced discrimination in other churches, Gagnon too believes that many people with disabilities feel unwelcome in traditional church settings. "What is so unique about the Abilities Church is that it gives disabled people the chance to inspire others through ministering in an inclusive environment," he says.

With the holiday season approaching, the pastors and their congregants are particularly excited to promote their ministry's messages of integration, inclusion, hope and faith.

In the short time that it has been active, it seems the church's messages have already gotten across, having generated interest from churches all over North America. As Castro relates, "we have [even] received calls from different faiths asking how they can apply the Abilities Church model to their respective communities." Clearly, the church is bridging the gap between the mainstream and special needs communities; fostering pride and confidence in exceptional people by giving them a forum in which to lead, teach, and inspire others, it is setting an example for others to follow. ■

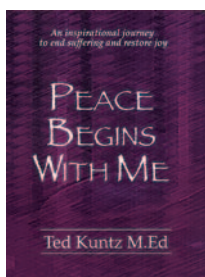
*To learn more about Abilities Church, visit [www.abilitieschurch.org](http://www.abilitieschurch.org)*

# & Classics

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

## Peace Begins With Me

By Ted Kuntz, M.Ed  
Ted Kuntz, 2005  
208 pages, \$24.95



When his son Joshua was diagnosed with a seizure disorder at five months old, family therapist Ted Kuntz was devastated. For the following five years, he carried his grief, pain, anger and hostility around like a ball and chain – ever-present and continually in the way of his happiness and relationships with others. Then one day, upon pulling into the driveway after a day’s work, the sight of Joshua waiting to greet him from a bedroom window led to what Kuntz refers to as his personal “epiphany”: the realization that the father he was reflecting back to his son was one filled with rage, fear and anxiety. Determined to become the dad that he wanted Joshua to see – a man genuinely happy, accepting, and at peace with his lot – Kuntz resolved to alter his way of thinking that very moment. Thus began a life-changing journey that completely altered the way Kuntz now approaches everything in life – from his son’s disabilities, to the meanings he ascribes to daily events, and even the way he breathes.

*Peace Begins With Me* is a collection of the lessons Kuntz learned on his quest toward inner peace. One quarter autobiography and three-quarters self-help, the author focuses less on his own experience and more on the universal affirmations and resolutions that all can apply. Metaphors and vignettes

consult a psychic out of despair in order to glean whether Joshua would live, or his resolve not to fill a prescription after being hospitalized for a spine fracture so that he could “feel” the pain and thereby accelerate the healing process. Kuntz’s assertion that his son’s seizure disorder was caused by toxins

*In my profession as a family therapist I counsel troubled people. Yet I couldn’t get my own life to work. I felt like a fraud. The knowledge and skills that I acquired as part of my professional training were inadequate to provide relief. I was desperate. Something had to change.*

- *Peace Begins With Me*

add interest and clarity to Kuntz’s ideas, which, although by his own admission are not novel, demand thorough consideration and a strong commitment to internalize on the part of readers sincerely interested in self-improvement.

Everyone from Oprah and Buddha to Abraham Lincoln and Anthony Robbins is quoted in this book, which may either delight or irritate readers. Additionally, some of Kuntz’s choices may raise a few eyebrows, such as his decision to

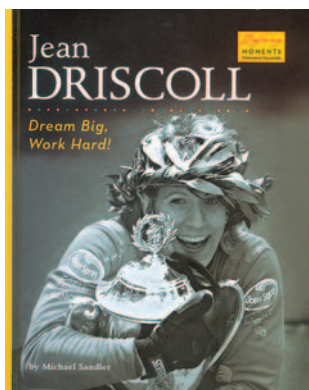
from a childhood vaccine may also feed unnecessary fear in parents grappling with the vaccine debate.

Still, *Peace Begins With Me* is an inspiring little book with immensely powerful lessons. For those who question the legitimacy of Kuntz’s step-by-step tools in creating lasting happiness and inner peace, one need only look to Kuntz himself for proof of their effectiveness. A therapist who takes his own advice, Kuntz’s outlook epitomizes joy, acceptance and satisfaction as a

result of having applied his own teachings. If you resolve to do anything this New Year, resolve to read this book. ■

## Jean Driscoll: Dream Big, Work Hard!

By Michael Sandler  
Bearport Publishing, 2007  
32 pages, \$21.79



by LAUREN SILVER

An inspiring book for children of all abilities, *Jean Driscoll: Dream Big, Work Hard!* chronicles American athlete Jean Driscoll, eight-time winner of the Boston Marathon, who was born with spina bifida in 1966. Beginning with her early

years, author Michael Sandler highlights the numerous challenges Driscoll has faced throughout her lifetime, and offsets those with even more examples of her tremendous accomplishments – such as teaching herself to ride a bike at age nine, and going on to participate in a variety of activities including soccer, basketball, and long-distance races as a competitive wheelchair-athlete.

accident at age 14 which left her in a body cast for 11 months: “The cast was a prison for Jean. She dreamed of escaping from it.”

Written in simple, concise sentences and presented in large font, *Dream Big, Work Hard!* is a valuable tool for children learning to read independently. Although readers will find some of the vocabulary

*Wheelchair soccer was nothing like Jean expected. It was fast. It was wild. It was the coolest thing she had ever done!*

*“Chairs were crashing and banging; bodies were flying,” she remembers. Over the next few months, she tried one wheelchair sport after another: racing, tennis, ice hockey, and even waterskiing. Jean was hooked.*

*- Jean Driscoll: Dream Big, Work Hard!*

From frequent falls and bullying, to dreams of being able to “run and play without having to work at it”, readers ages 9 to 12 will empathize with the difficult hurdles Driscoll had to contend with as a youngster and teen. The athlete’s pain is palpable in Sandler’s use of visual imagery to describe her feelings following an

new and potentially challenging, sophisticated words are bolded and defined in a glossary at the back. A timeline highlighting milestones in Driscoll’s life adds to the book’s appeal, while a “Just the Facts” section offers further insights into spina bifida and Driscoll’s career. Vivid pictures on every page convey Driscoll’s enthusiasm and passion for sports and show her celebrating her successes. Even more compelling, though, are pictures showcasing Driscoll in training, a reminder to readers of the tremendous efforts Driscoll had to invest in order to triumph.

Named after Driscoll’s personal mantra, *Dream Big, Work Hard!* will motivate all children experiencing any kind of setback on the path toward achievement. It sends the message that victories and accomplishments represent the culmination of incredible determination, patience, and sometimes, even sweat – valuable lessons, which everyone can learn from. ■

The advertisement is titled 'Sensory Tools and Solutions' in large, bold, red letters. Below the title is the logo for 'fdmt' (FDMT Enterprises), consisting of the letters 'f', 'd', 'm', and 't' in blue and green boxes. To the right of the logo, contact information is provided: '2211 de la Métropole, Longueuil, Qc J4G 1S5, Telephone: 450-321-5500, Toll free: 866-465-0559, Fax: 450-321-5503, Show room: 9 am to 4 pm Monday to Friday, www.fdm.ca'. The main image shows a young child sitting and reading a colorful book. In the foreground, there are several colorful, textured toys, including a weighted blanket and weighted lizards. The text 'Educational toys', 'Learning materials', and 'Special Education' is written in blue, green, and red respectively. A small caption reads 'Weighted blanket and weighted lizards'.



# The Role of the Eye Geneticist: Comprehensive Treatment for Patients and Families

## The fifth in Exceptional Family's special series on Eye Health and the Exceptional Child

ELIZA S. STROH, MS, Genetic Counselor  
ALEX V. LEVIN, MD, MHSc, Pediatric  
Ophthalmology and Ocular Genetics  
Wills Eye Institute, Philadelphia,  
Pennsylvania

**I**nside every cell in our bodies lies DNA, our own personal blueprint that tells our bodies how to grow, develop, and function. Our DNA contains thousands of different genes, each of which gives rise to a particular protein with a specific job

to do. Genetic disease occurs when the DNA in a particular gene is irregular, causing it to produce a protein which does not work properly.

Of the thousands of genetic conditions which cause impairment or disability in humans, approximately one-third involve the eye.<sup>1</sup> A genetic change may cause disease that affects only the eyes, but allows the rest of the body to function normally. Alternatively, because a particular protein may be used in many different tissues of the body, a genetic syndrome may affect more than one body function, such as vision, hearing, and bone structure.

Genetic disease of the eye can affect patients of any age, though visual

impairment in infants and children is more likely to have a genetic basis. Collectively, genetic disease of the eye is the most common cause of visual loss in children and young people of developed nations.<sup>2</sup>

Because genes are involved in the development of all parts of the eye, genetic disease may affect any aspect of eye anatomy. There are many different types of genetic eye disease, including those that affect the cornea, lens, iris, retina, optic nerve or more than one part of the eye. Specific genetic changes lead to diseases such as retinitis pigmentosa, cataract, glaucoma, and retinoblastoma. Other gene changes lead to conditions such as ocular albinism or defects in color vision. There is

1 Costa T, Scriver, C.R., and Childs, B. (1985). The Effect of Mendelian Disease on Human Health: A Measurement. *American Journal of Medical Genetics*, 21, 231-242.

2 Hurst, J.A. (1992). Genetics of Blindness. *British Journal of Hospital Medicine*, 47, 495-500.

an extensive list of genetic syndromes which affect multiple body systems in addition to the eyes, such as neurofibromatosis, Down syndrome and Marfan syndrome.

## What is an eye geneticist?

A clinical geneticist is a physician who specializes in understanding how genes instruct our bodies to develop and function, and how changes in those genes can lead to disease. Geneticists are also interested in how those genes are passed from generation to generation, and what the implications are for patients and their families. Because a diagnosis of a genetic disorder often means that other family members are at risk of being similarly affected, management often involves the extended family unit rather than the patient alone.

In recent years, our understanding of the genetic basis of many eye disorders has increased significantly, leading to a larger demand for clinicians who specialize in the genetics of eye disease. These physicians, known as eye geneticists or ocular geneticists, play a multifaceted role in the care of patients and families, whose needs can be extensive. Eye geneticists work with genetic counselors, clinical and research-based genetic testing laboratories, community resources for people with visual impairments, primary care teams and other medical specialists to provide comprehensive care for families affected by genetic eye conditions.

## Working toward a diagnosis of genetic eye disease

When a patient is affected with genetic eye disease or systemic dis-



ease with associated eye abnormalities, a specific diagnosis often makes it possible to provide the family with information regarding treatment options, the mode in which the condition may be passed on genetically, future expectations for function, and research opportunities.

Diagnosing genetic eye disease often involves multiple steps carried out by various professionals. The first clues to a diagnosis are gathered during a thorough eye examination by an ophthalmologist who specializes in genetic disorders which are often rare and unfamiliar to other eye doctors. The family may then meet with a genetic counselor who

works closely with the physician to specify a diagnosis. A genetic counselor may also present options for specific genetic testing, and can predict and explain the likelihood that particular family members will inherit the disease. He or she can also counsel and assist the family to cope with a diagnosis, and provide support in the form of information and community resources.

### **1** The pedigree: documenting the family health history

A fundamental aspect of the diagnosis of any genetic condition is careful documentation of the family tree or pedigree. Examining the health his-



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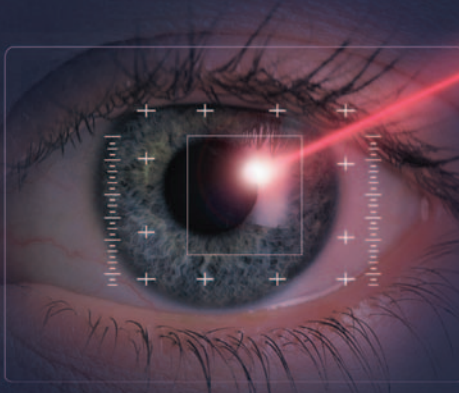
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tory of other members of the extended family may provide clues as to how the condition is inherited and may aid in the diagnosis of a particular condition. When record-

der, who should be monitored for signs of disease, and who could benefit from genetic testing.

*Even if the patient is the only known affected member, the eye disorder may still be genetic.* Genetic disease has to

nature of a disease goes unrecognized until someone familiar with the scenario, putting together various body problems in addition to the eye, makes the connection. For example, did you know that a serious cause of glaucoma called



*Our understanding of the genetic basis of many eye disorders has increased significantly, leading to a larger demand for clinicians who specialize in the genetics of eye disease.*

ing the family pedigree, the genetic counselor may ask about visual impairment in other family members, other medical issues, birth defects, major surgeries, and age and cause of death. A pedigree also indicates who else in the family is at risk for being affected by the disorder,

start somewhere in a family and the patient may be the first. Parents may be carriers without any prior knowledge. Parents and other family members may even have the disorder in such mild forms that it went undetected. Often the eye geneticist will ask to examine other family members. Sometimes, the genetic

Axenfeld-Reiger spectrum is associated with abnormally formed teeth and an abnormal belly button? The diagnosis may be very difficult even for the eye geneticist and genetic counselor. Together they can take the time to search medical literature and databases for a diagnosis that matches the patient's disorder.

## Exceptional children face challenges... Finances need not be one of them.

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- Do you know about all the financial assistance programs and incentives offered by the government? Do you have a way to cover the costs not covered by the government?
- Do you have appropriate insurance coverage in place to protect your child and the rest of your family?
- Did you know that setting up a discretionary trust can prevent a negative impact on your exceptional child's social benefits as a result of an inheritance?

If these issues are of concern to you, we need to talk. Having a disability since birth, I understand the challenges exceptional children can face.

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When a specific genetic change is identified within a patient or family, it may be possible to test for the condition prenatally. Some families are interested in the option of preimplantation genetic diagnosis, in which eggs are fertilized in the laboratory, tested for the genetic condition of interest, and only healthy embryos are selected for transfer. In some situations, parents may opt for testing of the baby during pregnancy. In other circumstances, parents have no interest in these techniques, but desire information to help prepare them for the chance of having an affected child. Because dealing with these issues can be difficult for families and decisions about reproduction are very personal, geneticists place great importance on educating families about their options in a non-directive fashion in order to facilitate the decision-making process.

## 2 Molecular genetic testing: pinpointing a genetic cause

In light of the increasing number of genes found to be associated with eye disease in recent years, molecular genetic testing for many eye conditions is now available. The eye geneticist or genetic counselor can provide information regarding the benefits and limitations of genetic testing. For some conditions, a mis-

diagnosis may be made which could have been avoided or now corrected with genetic testing. For others, gene therapy may be available. Genetic testing can help clarify the diagnosis and lead to more precise treatment and counseling. Since the benefits are specific to the condition, families stand to gain from proper education by a genetic counselor prior to making decisions about testing.

## Risk assessment: Who else in the family could be affected?

Using information from the family pedigree, past research, case studies, and/or from genetic test results, a genetic counselor provides the family with important information about how a particular genetic disorder is passed on. This information can be used to determine who in the family is or is not at risk, and who may be in need of an eye examination to look for signs of the disorder. In addition, a genetic risk assessment quantifies the chance that any future children will be affected with the disease.

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## 3 Support, education, and resources

The genetic counselor and ocular geneticist may provide families with disease-specific, patient-friendly resources including literature, research, useful websites and general information on genetics, eye anat-

my and disease pathogenesis. They may also clear up misinformation that families have gathered on the internet, which can often confuse and mislead.

Following a diagnosis of a serious vision disorder, families may seek further support from other professionals such as social workers, psychologists, low vision support workers or family therapists. Other resources include financial assistance and early-intervention services. The eye

A diagnosis of genetic eye disease often requires long-term follow-up to continue to address the needs of families. Appropriate services and management should be offered to other family members who may be at risk, including additional children who are born into the family.

#### **Collaboration with other specialists**

As many genetic diseases are known to affect other organ systems beyond the eyes, a proper unifying diag-

Geneticists often serve as resources for other clinicians and specialists without specific training in the field of genetics, and may thereby assist in the diagnosis of patients outside their range of care. Since there are relatively few eye geneticists, they often play a role in the diagnosis of patients beyond their community, region, or country.

#### **Research and communication**

Our understanding of genetics and how genes cause disease is constantly advancing, and geneticists must stay informed of advances in research. By being aware of new treatments and therapies, ocular geneticists strive to ensure that their patients receive the best, most up-to-date care available. Active involvement in the scientific community also requires geneticists to share their own findings and case studies with colleagues, through publication and lectures, so that other patients may potentially benefit from these results. ■

*Some parents benefit from contact with other parents of children with the same or similar diseases, and these interactions can be facilitated.*

genetics team has access to these resources and can coordinate referrals as needed.

A genetic counselor may also connect families to community resources, including groups that provide services for the blind and those with low vision, as well as support groups specific to the eye condition. Some parents benefit from contact with other parents of children with the same or similar diseases, and these interactions can be facilitated.

nosis is essential for complete health-management. An eye geneticist may therefore refer patients to other medical specialists as needed, including audiologists, neurologists or cardiologist, depending on the manifestations of the disease in question. The complex nature of genetic disease and the far-reaching implications that such conditions can have on families require specialized management from multiple sources.

**Eliza S. Stroh** is a graduate of Arcadia University's genetic counseling program in Philadelphia, PA. A previous Ph.D. candidate in the field of genetics, she has experience in genetic research and undergraduate education.

Following completion of a pediatric residency, ophthalmology residency, and paediatric ophthalmology fellowship, **Dr. Alex V. Levin** (M.D., MHSc, FAAP, FAAO, FRCSC) was a professor in the Departments of Pediatrics, Genetics and Ophthalmology and Vision Sciences at The Hospital for Sick Children, University of Toronto, before returning to Wills Eye Institute as Chief, Pediatric Ophthalmology and Ocular Genetics.

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

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# In

# Focus

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

## It's OK to Be Angry – How You Express it May Not Be



PHOTO: JULIAN HABER

All parents have been driven to anger by their children at one time or another; it comes with the territory of parenthood. For many exceptional parents, however, the potential to become angry is often magnified. Having a child with a disability can put a strain on a marriage, for example. Some spouses find themselves playing the “blame game” with each other around a child’s diagnosis, and may argue about everything from sharing the responsibilities, to treatment options, to expenses. Or they may experience frequent anger at doctors, teachers, strangers, or even friends and family members who don’t “get it” when it comes to the needs of their children.

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Anger is an acid that can do more harm to the vessel in which it is stored than to anything on which it is poured.

– MARK TWAIN

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Depending on their disorders, children themselves may also be more prone to daily frustrations that contribute to their own anger, or have difficulty regulating their emotions in general.

Anger is a natural human instinct, like fear. *Feeling* anger is okay. How you *express* it may not be.

When it’s appropriately expressed, anger can often result in positive change. Civilization largely depends on our outrage against injustice, for instance. On a more personal level, anger over inadequate services for one’s child with special needs can motivate a parent to become an effective advocate on his or her behalf.



Anger can also be an important step toward achieving good mental health. For example, it's a necessary, healthy stage in the process of mourning – and not just in relation to a death. Mourning can be associated with divorce, a medical illness, the loss of personal goals, dreams or anticipations of how one’s life would unfold, or a whole host of other crises. People who never reach, or get stuck at, the anger stage of mourning often never resolve their issues.

Anger becomes a problem when it develops into a predictable pattern of inappropriate behaviour, or when it becomes a chronic condition rather than an occasional expression of emotion. When adults or children can't get past their anger, or when they express it in a manner disproportionate to the triggering event, it is no longer healthy. And as Mark Twain suggested, holding it in can be harmful too.

But many angry individuals don’t even recognize they have a problem. They often think the problem lies with everyone else – with children, parents, a spouse, a teacher, a boss, or “the system”. Moreover, anger can be associated

# Anger's Fuel: Cognitive Distortions

Both children and adults may suffer from cognitive distortions – automatic, exaggerated, and irrational thoughts that fuel negative behaviours. In *The Anger Control Workbook*, psychologists Matthew McKay and Peter Rogers identify six categories of thought distortions that are likely to increase feelings of anger. They offer the following alternative coping thoughts and techniques, which can be adapted to almost any age or level of function.

	BLAMING	CATASTROPHIZING
DEFINITION	The underlying belief that people are the cause of your problems.	Making a mountain out of a molehill.
PROBLEM	By blaming others, you relinquish the power to change the situation yourself. You cast yourself in a passive, helpless role instead of taking ownership.	By magnifying the situation, you're setting yourself up to become hostile over a distorted, exaggerated version of it, instead of dealing with reality.
THOUGHT DISTORTION	"I couldn't do the project because the teacher didn't explain it right. She really has it in for me!"	"She shouldn't have come over if she had a cold. Now I'm going to catch it and give it to my sick grandmother, and she'll die!"
REPLACE WITH COPING THOUGHT	"That was frustrating but I've learned something. Next time I'll check with her as I plan the project, to make sure we're on the same wavelength."	"She probably didn't do it deliberately. And I can do something to make it ok. I'll just stay away from Granny for a few days."

with some very gratifying emotions. Expressing anger can feel empowering and proactive – traits that are considered virtues in our society.

Even if the anger no longer feels good, sufferers of chronic anger may be locked into a cycle – always blaming outside influences for

making them angry and preventing themselves from seeing the positive in situations.

Long-term anger is not just a barrier to happiness; it can also contribute to health complications, from physical discomfort to far more serious problems. And that's not just true of anger that's expressed in intermittent, explosive rages. Equally dangerous is constant "low-grade" anger – the bitter, irritating, grudge-carrying hostility of a person whose temper is always simmering just below the surface, ready to boil over.

Now for the good news: Just as there are many ways in which inappropriate anger can develop and be expressed, there are many ways in which it can be controlled – such as via modelling healthy expressions of anger for children,

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INFLAMMATORY GLOBAL LABELLING	MISATTRIBUTIONS	OVERGENERALIZATIONS	DEMANDING/ COMMANDING
Making sweeping, negative judgments about people whose behaviour you don't like.	Jumping to conclusions; mind-reading	Making problems look bigger by using words like "never," "always," "nobody," "everybody," etc.	Turning your personal preferences into the Ten Commandments.
By turning someone into a one-dimensional stereotype, you're fuelling your anger.	By assuming you know someone's motives, you risk being mistaken and feeling foolish later.	Again, by exaggerating the situation, you're setting yourself up to get angry and avoid dealing with the reality.	By judging others according to your personal beliefs, you're bound to be disappointed and angry.
"What a !@#\$%. He doesn't know anything."	"She did that deliberately. She wanted to embarrass me in front of everyone."	"My parents are always blaming me. It's never my fault. But my brother always gets away with everything!"	"The game is played this way. And I always go first!"
"He's not a jerk, just someone who wasn't properly trained to do his job."	"Getting angry won't help me figure out what's really going on. I need more facts. If I'm right, I'll be able to prove it. If I'm wrong, I won't look even more foolish."	"It doesn't always happen this way. There are lots of exceptions."	"It's possible her way could be fun too. And it's her game, her house, her party. She should make the rules this time."



or employing relaxation techniques. Medications can sometimes be helpful. There are also therapies designed to teach anger-management and impulse control, improve communication, and alter thinking and feelings (cognitive-behavioural therapy).

Parents can also help their children to learn to self-regulate their emotions, by teaching them that while anger is a natural feeling, there are right and wrong ways to express it. By encouraging kids to make their own list of "Anger Do's and Don'ts" (which could be a fun learning activity, with the right approach), and reinforcing appropriate expressions of anger whenever possible, parents can help their children to differentiate between right and wrong expressions of anger on their own.

Whether you or your loved one follow that method or any other, the most important thing is to be aware of the mental and physical health risks associated with chronic and/or inappropriate displays of anger, and to seek treatment for it. Anger needn't be a personality trait. At least, not a lifelong one! ■

**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.

## Santa's not the only arbiter of who's naughty or nice

Despite children's best efforts to behave in school, teachers, staff and fellow classmates may still perceive them as bad apples, research out of Manchester Metropolitan University reveals. In a study of 100 four- and five-year-olds at four English nursery schools, professors Maggie MacLure and Liz Jones found that certain behaviours exhibited by the preschoolers were almost guaranteed to earn them negative reputa-



## Successful experiment holds promise for people with paraplegia

Researchers at UCLA's David Geffen School of Medicine and the University of Zurich have prompted paralyzed rats to walk and even run, using a combination of treadmill exercise, electrical stimulation below their injury sites, and the chemical-messenger drug serotonin, to activate the animals' spinal nerves. The experiment involved eight rats whose spines had been severed, leaving their hind legs completely immobile.



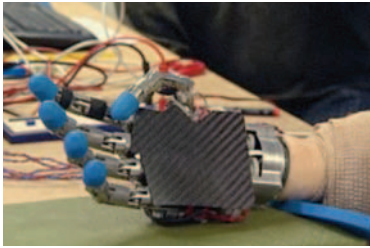
While the rodents regained involuntary leg movement after about seven days of therapy, maximum results were attained after multiple weeks of intervention. Earlier trials revealed that mammals' spines contain nerve circuits that can be stimulated to move the legs of those with paraplegia, even in the absence of feedback from the brain. The latest results present an alternative to stem-cell regeneration of damaged nerves and mark the first time that full weight-bearing and sustained stepping was achieved. In order to be transferable to humans, a prosthetic will have to be created that will deliver enduring electrical stimulation over all of the areas affected by a spinal cord injury, said Swiss lead researcher Dr. Gregoire Courtine, an achievement, he noted, that may take a number of years.

tions in class, particularly if those behaviours were deemed symptomatic of greater personal problems. Conduct that was frowned upon included frequent non-compliance with adults' requests, displays of physical aggression, being noisy during line-ups, repeatedly calling out during lessons, and sitting improperly. Teachers also tended to attribute some children's unsavoury behaviours to undiagnosed conditions, like autism or deafness. Students' reputations were also influenced by educators' perceptions of their upbringing, parents and home life.

In order to increase their chances of remaining in good standing, MacLure and Jones said kids need to be aware of "classroom culture" from an early age, and know which behaviours are appropriate and valued in school, versus those that are not. Children must also be skilled at interpreting mixed messages and reading others' emotions. MacLure encouraged teachers not to be hasty in correcting and judging students, adding that kids develop self-perceptions based on their thoughts of how others see them. She cautioned that children labelled "bad" may enact self-fulfilling prophecies and grow into "bad" young adults.

## How about a Smarhand to control your smartphone and Smart car?

A consortium of scientists from Sweden and Israel has developed the first robotic hand that successfully restores the sense of touch for people with amputations. As reported by Sky News, the



Smarhand enables wearers to control the tightness of their grasp when holding objects, and make gestures such as pointing. Equipped with over 40 sensors in its fingers and four motors in its palm, the Smarhand is mechanically attached to a socket connected to a person's arm at the amputation site. The socket contains receptors that stimulate arm nerves when fingers come into contact with objects. According to project coordinator Dr. Fredrik Sebelius, the Smarhand is most appropriate for individuals with lower arm amputations, as they have more remaining muscles to work with than those whose amputations are above the elbow. Researchers at Tel Aviv University and Ireland's Tyndall Institute are currently developing a "cuff electrode" for people with higher amputations. The device will serve the same purpose as the current socket, only it will be wireless and will necessitate surgical implantation.

## COMING SOON: North America's first exceptional amusement park

Children and adults with physical and cognitive disabilities will soon have an amusement park tailored to their exclusive needs and enjoyment, thanks to a one-of-a-kind attraction slated to open early in 2010. Morgan's Wonderland in San Antonio, Texas, spans 25 acres and is named after Morgan Hartman, the 15-year-old exceptional daughter of philanthropists Gordon and Maggie Hartman, who donated the first \$1,000,000 toward the park's creation. By the time it's completed, "The World's First Ultra Accessible Family Fun Park" is set to cost approximately \$27 million, funds largely amassed by local non-profit organization Sports Outdoors and Recreation (SOAR). Morgan's Wonderland will be part of a larger soccer complex and adjacent baseball and track and field facilities, which will be open to players of all abilities. In addition to an eight-acre lake filled with a variety of fish, the attraction will also boast Braille signage, an accessible carousel and trains, a sensory village, and a designated rest area for service animals. Admission will be free for visitors with special needs.



## Lack of motivation in people with ADHD is chemically-based



Scientists at Brookhaven National Laboratory in Long Island, NY, have discovered that the brains of people with ADHD lack key proteins in their limbic areas – the parts responsible for motivation and reward. As published in the *Journal of the American Medical Association*, researchers compared the brain scans of 44 people without ADHD to those of 53 people who were diagnosed with the disorder, but never treated. The scans of those with ADHD revealed lower levels of receptors and transporters of dopamine, an essential chemical responsible for mood regulation. The findings add to earlier research which pinpointed brain abnormalities in people with ADHD in the regions responsible for controlling hyperactivity and attention. Some members of the ADHD community are welcoming the latest research as further proof that people with the disorder are neither intentionally wayward nor the result of bad parenting.



# My Life with Autism

◆  
*The story of a young man  
determined to succeed*

by YOSEF ROBINSON

**I** am a 27-year-old Montrealer, and I have high-functioning autism. Autism is a condition characterized by social, communication, and behavioural impairments. When I was two, I was diagnosed with “autistic tendencies” (diagnostic categories were less precise in the mid-1980s than they are today). I couldn’t speak and would not respond to my name when spoken to, and I exhibited a number of other signs of the condition, such as obsessively lining up toys in a straight line. Soon after I was diagnosed, my parents enrolled me at Montreal’s Giant Steps, a pioneering school for children with autism. Founded by an innovative music therapist named Darlene Berringer, Giant Steps strives, among other goals, to help students integrate into regular schools. There I received a wide array of supports, including

music, speech and occupational therapies. I was also taught social skills and activities of daily living, like how to shop at grocery stores and how to use money. I made much progress in learning how to speak and interact socially, and acquired the necessary tools to begin attending a mainstream kindergarten part-time at the age of five.

I spent the following three years at a public elementary school, while frequenting Giant Steps a few times a week. In addition, I went to afternoon Hebrew school twice weekly. (This was important for both my family and me, as we are Modern Orthodox Jews, i.e., Jews who adhere to the precepts of Orthodox Judaism while integrating into modern life.)

From grades 4 to 6, I attended a local Jewish school where the curriculum was taught in English, French and Hebrew. This presented a certain

challenge for me, having come from a public school where most of the lessons had been taught in English with only a bit of French. My parents chose that school primarily because the staff was caring and sensitive to my needs. While I still attended Giant Steps during fourth grade, after that I was more or less fully mainstreamed – though Berringer brought a few of my fifth grade classmates together, whom she sensitized to my condition. To further assist me with social integration, she also organized various games that we played together. Nevertheless, I still found social settings difficult. Integrating into others’ conversations during recess and lunch breaks was especially tough, though I did make a few friends during those years.

I completed my high school studies at a local Modern Orthodox school, where I excelled at academics. Though I made efforts to befriend

my peers, I did not develop further on a social level in a significant way. My schoolmates were not too receptive to my efforts, in large part because they were ignorant about my autism and the challenges I faced daily. In general, I think students in mainstream schools should get to know people with disabilities more.

After high school, I spent a year in Israel pursuing higher education at a men's seminary (called a yeshiva). Studying in Israel is a popular tradition among many Orthodox Jewish high school graduates. I had a good time overall, though much of the material I studied was pretty challenging, both because it was in Aramaic or Hebrew and because the concepts were quite sophisticated.

Upon returning to North America, I decided to earn my Bachelors degree in Geography at Rutgers University in New Jersey. I did not need much outside help with my studies, though I went to a writing tutor in my very first semester, and my parents went over many of my papers. I also worked as a note-taker for a student with learning disabilities. In my senior year, I wrote an honours thesis on comparisons between the Armenian and Jewish communities of Montreal.

Living away from home was daunting at first, but I did not experience such a hard transition. While I got along with most roommates, I had problems with some whose personalities clashed with mine. Living on my own has made me much more self-reliant than I would have been had I remained in Montreal.

Following Rutgers, I attended Ohio State University for two years as a Masters student in City and Regional Planning. I did not need much help with my papers



Yosef at 7 months.

In the fall of 2007, I returned home to Montreal at Berringer's invitation to join a "collaboratory" or group that she was in the process of establishing. The collaboratory was comprised of qualified young adults with high-functioning autism and Asperger syndrome who wished to pursue careers but have a hard time adjusting to the social demands of work in the "real world". One of Berringer's goals in founding the collaboratory was for her to facilitate connections between members like myself and prospective

My schoolmates were ignorant about my autism and the challenges I faced daily. I think students in mainstream schools should get to know people with disabilities more.

there. Not long after graduating and completing an internship, I held a brief planning position in Jacksonville, Florida.

employers, who would then outsource relevant work to us, without the need for us to work in-house. I was connected with various architects

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≠ Illiteracy  
≠ Non-communication  
≠ Loneliness  
≠ Poor Quality of Life

**Autism**  
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Let's work together!

and urban planners, and I worked on a number of projects. Berringer also instituted activities for collaborative members that highlighted the importance of exercise, nutrition and sleep, and taught us social and

Planning and Environment Department. The program will broaden the urban planning skills I already have and includes an internship in my field, which I hope will lead to a full-time job. I am now studying the

the High Holidays this year, I also conducted services at an assisted-living residence.

I have certainly come a long way from when I was little, when it took a big



I have certainly come a long way from when I was little, when it took a big effort for me simply to speak.

work etiquette, including the skills needed to interact appropriately with coworkers.

environmental impacts of development projects and policies, and learning how to make an environmental impact statement, which is a report that outlines a particular issue of concern and recommends a certain action to rectify the problem.

effort for me simply to speak. In addition to elementary and high school diplomas, I now have Bachelors and Masters degrees under my belt, and can speak French and Hebrew in addition to my native English! I have strengths in areas such as research, attention to details and organization. I have a broad range of interests, including geography, current events and music. Despite my autism, I can do many things. ■

Last summer, I left the collaborative to pursue a graduate degree in Environmental Assessment at Montreal's Concordia University as part of its Geography, Urban

Most recently, I was hired to lead morning prayer services a few times a week for Jewish seniors at a local long-term care facility. Over

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# FROM THE FOOTHILLS TO VANCOUVER 2010



L to R:  
Jared Carbert,  
Hayden Fairley  
and his dad/coach  
Heath, and  
Ben Biermann, at  
the K1 Race  
on Edmonton's  
Rabbit Hill.

## Helping Competitive and Recreational Skiers Reach their Peak Performance

by JARRED COXFORD

**W**ith only weeks to go until the start of the Vancouver 2010 Winter Olympics, Edmontonian Viviane Forest is anxiously awaiting the games' conclusion. That's because the end of the Olympics signifies the beginning of the Paralympics, set to launch in Vancouver and Whistler on March 12. For Viviane, an award-winning alpine skier with visual impairments, the international multi-sport event for athletes with physical disabilities represents a culmination of years of training and perseverance and a chance to showcase her talents to the world. Now competing on the World Cup Circuit, Viviane got her start at the Canadian Association for Disabled Skiing (CADS), just a few years ago.

"CADS gave me excellent opportunities and great instruction," said Viviane. "The volunteer [instructors] helped me find equipment and arrange transportation. They understood what a visually-impaired person requires, and were very committed."

A 30-year-old institution, CADS aims to enrich the lives of people ages six and older with physical and/or cognitive disabilities by enabling them to actively participate in recreational and competitive skiing and snowboarding, via instruction and the provision of adaptive equipment, such as sit-skis. CADS' influence spans the True North with over 1000 participants nationwide and divisions in nine out of 10 provinces. Through the organization, exceptional athletes are also given the

opportunity to compete with peers of similar abilities.

According to Darlene Cathcart, the volunteer coordinator at CADS Edmonton, the organization's long-standing success and popularity can best be attributed to its volunteer coaches, who act as skiers' mentors and support their every stride. "All CADS programs are run exclusively [by] volunteers. The skills and expertise these people bring to CADS as board members and ski instructors are invaluable. From teaching learn-to-ski and snowboard programs to training elite athletes, CADS would not exist without our dedicated volunteers," she said.

All instructors are encouraged to earn their Level One Certification

based on weekly training sessions which give them basic skills to teach skiers with disabilities. Students receive one-on-one lessons and are constantly supervised; volunteers even escort them on lifts and while descending hills.

Viviane knows the value and dedication of the volunteer instructors firsthand. In 2007, she joined CADS' Edmonton Grass Roots Race Program, founded by volunteer head coach Heath Fairley. "Heath is the individual from the first day who believed in me, and recognized my potential," said Viviane. "He was my coach, my guide, found me all of my equipment, and took his own personal time and resources to ensure I was able to participate in all opportunities to race."

### A personal connection

Heath began volunteering as an instructor for skiers with visual impairments in 2004 then came to CADS Edmonton in 2005. An avid skier, Heath's ultimate goal – besides sharing his love of skiing – was to get his 16-year-old son, Hayden, on the slopes by his side. Hayden was born with spina bifida and hydrocephalus,<sup>1</sup> and while he does not use a wheelchair, he experiences challenges around his mobility.

"Since Hayden does not have the lower leg muscles that we all have, it's much harder for him to stand on skis and maintain his balance

<sup>1</sup> Spina bifida occurs when the spinal column fails to develop properly resulting in varying degrees of permanent damage to the spinal cord and nervous system. Depending on the location and severity of the lesion, paralysis of the lower limbs may be either partial or complete. 80% of those with spina bifida also have hydrocephalus, which occurs when spinal fluid pools on the brain and requires a shunt to drain it in order to relieve pressure on brain tissue.

<sup>2</sup> Outriggers are skis with forearm crutches that have miniature skis on them, used to facilitate balance and turning on hills.



Sixteen-year-old Hayden Fairley takes a break while skiing on Rabbit Hill.

without the support of [adapted skis called] outriggers<sup>2</sup>," said Heath. "CADS was able to teach Hayden how to properly use outriggers and

Edmonton Grass Roots Race Program in 2007. In the spring and summer months, he trains on dry land to prepare for the winter season. Hayden

I like getting out and trying new things. [The program] lets me hang out with friends who I normally don't get to see.

he was able to learn from others who had similar challenges to himself."

In 2006, Hayden enrolled in the Learn to Ski program; he joined the

adores his time on the slopes and is grateful for the opportunities that CADS Edmonton has given him. "I like getting out and trying new things," he said. "[The program]

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Paralympian Viviane Forest with friends Matt Sinn and Jared Carbert.

lets me hang out with friends who I normally don't get to see."

## Highlighting their potential

Hayden's mother, Mia, credits CADS for bringing out the best in her son and others with special needs. A volunteer sledge hockey instructor with CADS Edmonton, Mia speaks

wonders of the organization. "[CADS] shows these students that they could do whatever they want to do. It gives them a level of freedom, independence and maturity and has allowed Hayden to be a lot more active than he [otherwise] would have been."

Heath agrees. "I've noticed such a huge confidence boost in all of them," he said, referring to the skiers

involved with CADS Edmonton. "They're used to going to school and being the token 'guy off to the side' [when it comes to sports], whereas when it comes to skiing they could not only participate [with able-bodied athletes], but they could even ski better than them."

Despite her rise to Paralympian status, Viviane still feels very much a part of the Edmonton Grass Roots Race Program and continues to be an active CADS member. "I still register every year with [the program]," she said. "I really like to meet with all the athletes on practice nights and it is very rewarding to see the confidence those young adults [gain from] such an opportunity."

As Viviane prepares to go for the gold between March 13 and 21 in numerous ski events, including the downhill and giant slalom competitions, Heath will be among the thousands of Canadians eagerly cheering her on. "I feel both proud and excited that CADS' Edmonton Grass Roots Race Program was able to introduce her to the sport of ski racing," said Heath, of his former student.

Asked whether he'd like to see Hayden in Viviane's place one day, Heath replied, "Absolutely. I'm very proud of my son and the other two boys he races with; they're working very hard on their off-snow conditioning and nutrition so they can be in top shape to start the new ski season. They've all come a long way and I do believe seeing Viviane's success only helps push them to be the best they can be. I hope Hayden sees what you can achieve when you are driven and focused on achieving a goal." ■

*For more information on the Canadian Association for Disabled Skiing visit [disabledskiing.ca](http://disabledskiing.ca), or visit CADS Edmonton at [cadsedmonton.ca](http://cadsedmonton.ca)*

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# imprints

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

**There are those who identify a social injustice and wish for it to be rectified.**

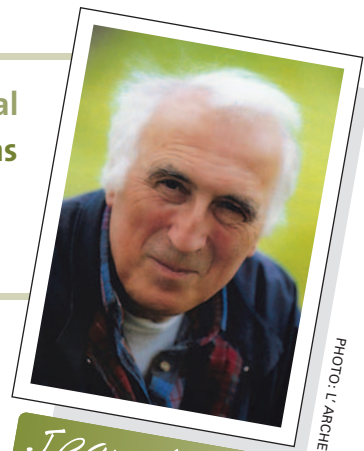
Jean Vanier not only recognized the isolation and loneliness of people with intellectual disabilities who were institutionalized during the 1960s and 70s, but resolved to do something about it.

Disheartened by their plight, the then 36-year-old son of former Governor-General Georges Vanier purchased a small home in Trosly-Breuil, France, and invited two men with intellectual disabilities to leave their institutions and move in with him. Vanier drew inspiration from the biblical story of Noah, and named the house "L'Arche" or "The Ark".

**I believe that those we most often exclude from the normal life of society, people with disabilities, have profound lessons to teach us. When we do include them, they add richly to our lives and add immensely to our world.**

The year was 1964, and as Vanier began to travel globally to share the lessons he had learned from his experience, his revolutionary concept of an inclusive community based on compassion and mutual respect caught on. Canada opened its first L'Arche home in 1969 and by the 1970's, L'Arche became an international movement. Today, over 132 L'Arche communities in 35 countries offer programming, workshops and social opportunities for people with intellectual disabilities who live with their caregivers and friends in small homes that are integrated into local neighborhoods. In Canada, L'Arche has approximately 200 homes and day programs in 30 communities from Vancouver Island to Cape Breton.

Although he no longer carries formal leadership within L'Arche, the 81-year-old Vanier continues to live with people with disabilities and to share his vision through speaking and writing. His leadership and humanitarian work have earned him international recognition and numerous awards, including the Companion of the Order of Canada, France's Legion of Honour, and the Pope Paul VI International Prize. Most recently, Vanier was named the Nation Builder of 2008 by *The Globe and Mail*. ■



*Jean Vanier*

For more information on L'Arche, visit [www.larche.ca](http://www.larche.ca)

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## With a Little Help from our Friends (and Family)

by STACEY MOFFAT

The unpredictability of life can be scary and overwhelming, particularly for people with special needs like my six-year-old son, Carter. Fear and anxiety around the unknown are emotions he encounters routinely. As his mother I can certainly relate, for I have been experiencing these same emotions off and on since the day he was born. I am worried about what the future holds for my precious son, who has a global developmental delay and is non-verbal.

In addition to being born with a cleft palate, Carter was recently diagnosed with childhood apraxia of speech (CAS), which in lay terms means that Carter's brain does not connect with his mouth to tell it what to do in order to talk. As a result, he communicates via sign language. Carter also tends to get extremely emotional when subjected to sensory overload or placed in anxiety-provoking situations that threaten his sense of security; a visit to the doctor or barber, for example, almost always leads to Carter crying, signing "all done" and shaking his head "no" – clearly wanting to escape the unsettling situation.

It should have come as no surprise, then, when a day at the circus when Carter was four did not go as smoothly as hoped. Seated in the middle of a row and locked in by boisterous toddlers and their parents, Carter became especially distressed when the ringmaster welcomed



*Stacey Moffat and sons  
Jack, 4, and Carter, 6.*

everyone in attendance by microphone. We left before the show began, squeezing past everyone and shuffling along the row, struggling to gain freedom. More than feeling helpless and sad because Carter had missed the show, I was also filled with regret for not having predicted that the noise might pose a potential problem.

Last year, though, our family shared an experience which filled me with encouragement and hope for the future. For Carter's fifth birthday, my mom and I decided to take him and his three-year-old brother, Jack, to see Thomas the Tank Engine live, at a local theatre.

Thomas is Carter's favourite character, so it seemed like the ideal way to celebrate his big day.

Determined not to replicate the circus scenario, I investigated seating options prior to purchasing tickets to the show. As luck would have it, a loge section with four single chairs was available. Separated from the congestion, these seats were optimal. Nevertheless, I was on edge until the show began, because I didn't know how loud it would be or how Carter would react to new and unusual events unfolding before his eyes.

My mom's presence helped to ease my anxiety. She is extremely patient with Carter and learned all of his signs in order to be able to communicate and interact with

him. Her efforts are reflected in the strong bond she and Carter now share. That day at the show, she understood that things might not work out and that Carter and I might have to leave suddenly. She and I had discussed our backup plan: If Carter could not handle the noise level, she would stay with Jack for part of the show so that he could enjoy it for a little while. Carter and I would wait for them in the lobby.

When the lights finally dimmed, Carter planted himself in his grandma's lap and clung to her so tightly I was sure he would leave marks on her neck. Watching his anxiety transform into sheer delight when Thomas finally appeared onstage confirmed to me that the outing had

## I struggle with a fear of the unknown, uncertain about what the future holds for my son.

indeed been a success. Yet as excited as Carter was to see Thomas, the unpredictability of the unknown still contributed to his apprehension. In the comfort of his grandma's arms and with the support of his family, however, he felt safe and secure and was able to truly enjoy the show.

### Looking ahead

It has been a little more than a year since this milestone event, and Carter's signing vocabulary has grown to include a variety of signs including food items, his favourite toys, modes of transportation, specific clothing items and colours. We've also created signs that enable Carter to name specific family members, as well as friends. He interacts with a variety of people. While he continues to plug away at speech therapy and oral motor exercises, he is also starting to use a voice output system together with signing.

Chronologically, our son is six years old. Developmentally, however, he is about three and still non-verbal. Although Carter has made tremendous gains in the area of receptive language over the past couple of years, he still has a lot of catching up to do. To that end, when explaining things to him it's hard for us to know how much he comprehends. Despite the stress Carter encounters in novel environments, fortunately he doesn't put up much of a physical struggle and allows me to take him by the hand or carry him in to various appointments.

We have been told that Carter will someday have a functional vocabulary, which is wonderful news. But the road will be a long one, with extensive interventions and therapy along the way. Time after time we are faced with the questions: Where do we go from here? How old will Carter be when he can finally speak a full sentence? Will his speech be intelligible to others? With limited speech, how well will he function in society?



*Carter and his grandma share some quality time.*

These questions plague me, and at times it can be challenging to ignore them. I struggle with a fear of the unknown, uncertain about what the future holds for my son. When my emotions overwhelm me, I think of my husband and his positive attitude toward Carter, and about life in general. My husband is very reassuring whenever I feel frustrated or worried about Carter's progress. He is open to trying anything and everything in order to help Carter reach his full potential – even if some of the interventions we try are unsuccessful. I think about my mom who always listens to me vent without judging or trying to fix my problems. And I think about my friend, the mother of two children with special needs. She has been a wonderful source of information and a great source of support and encouragement. I think about the dedicated therapists who have been working with Carter, who are passionate about seeing him succeed. Then I try to picture myself in Carter's shoes by thinking back to his fifth birthday with Thomas. And I tell myself that if Carter can repeatedly put his trust in family and therapists in order to take life as it is handed to him, I certainly can and *will* do the same. ■



# Ask the Expert

## When the Holidays are Overshadowed by Grief

**Q** Last February, my sister lost her newborn son Gregory to congestive heart failure. Gregory had hypoplastic left heart syndrome or HLHS (a rare congenital defect where the left side of the heart is underdeveloped) and died at 12 days old. Gregory's death shook our entire family and for three solid months following his passing, my husband, parents, and I grieved alongside my sister and brother-in-law and did whatever we could to support them and their four-year-old daughter, Abby. As Christmas approaches, their family is understandably experiencing a hard time. While my brother-in-law seems to be coping a bit better and is trying to embrace the holiday spirit for Abby's sake, my sister is planning effectively to "cancel" Christmas. There will be no tree in their home, no exchange of gifts (except maybe for Abby) and no mall visits to Santa.

I understand that my sister is in pain, I just wish she could put her emotions on "pause" for the next little while and recognize that her decisions will not only ruin Christmas for Abby, but for the rest of us.



PHOTO: LAWRENCE CLEMEN

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

**A** The loss of a child has a profound impact on immediate and extended family as your letter poignantly illustrates. It can be so excruciating to witness the prolonged suffering of others that commonly we become conflicted about wanting to respect their feelings while hoping that they could simply get over them and move on.

Your wish to make the pain go away has taken on an even greater sense of urgency with Christmas approaching. If only your sister would allow for its full celebration, you reason, life would be normalized and she might be cheered up at least temporarily. Otherwise, Abby as well as the rest of the family will be disenfranchised from experiencing most of the meaningful rituals and special festivities associated with the holiday season.

It needs to be said at the outset that life will never again be the same for anyone who has experienced a loss of the magnitude you describe. Evidence of the tear in the fabric of one's life remains even once mended. That is not to say that people should grieve endlessly. Rather, a process of mourning must occur, the outcome of which is to find a place within to

preserve the person lost, freeing up the survivor to go on.

While many of us know about the predictable five stages of grief that have been identified by famed psychiatrist Dr. Elisabeth Kübler-Ross, what tends to be less familiar are the number of variables that come into play in the mourning process. The

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**McGill Youth Study Team**



type of death — sudden or anticipated, peaceful or violent; the timeliness of it — whether the person lived a full life or had it cut short; the relationship to the deceased — parent, child, sibling or friend; and the emotional tenor of the relationship — comfortable or conflicted, close or detached, are only some of the considerations. These, combined with the individuality of the person experiencing the loss, mean that the mourning process is unique for everyone.

Consider your own response to Gregory's death. As family members less directly affected by the loss of a child than his actual parents, your mourning and that of your husband and parents likely ran most of its course in the three months of intensive grieving that you shared with your sister and brother-in-law.

Gregory's parents, by contrast, have had to confront his empty crib, both literally and figuratively. After anticipating his birth for nine months and bringing Gregory into the world, they were forced to say goodbye to their beloved baby as well as to so many of the hopes and dreams which he embodied. Like all expectant parents, they must have had a huge emotional investment in the pregnancy and birth, forcing them to contend with a range of emotions including anger, despair, and guilt.

Still, even two parents mourning for the same child may show varying levels of grief and widely differing expressions of it. As you have observed, your brother-in-law seems to be further ahead in his own process of grief or at least willing to go through the motions of celebration for others' sake. This can be explained in terms of the attempt of the couple to cope with their overwhelming emotions by unconsciously

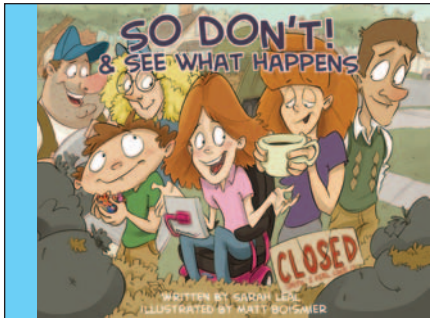
assuming complimentary roles in which each partner may take a turn to be strong so the other can mourn. While it is an effort to adapt, it can feel like an emotional seesaw.

It would be important to recognize that with Christmas on the horizon your sister's sense of loss may be heightened. Milestones such as holidays and birthdays tend to highlight

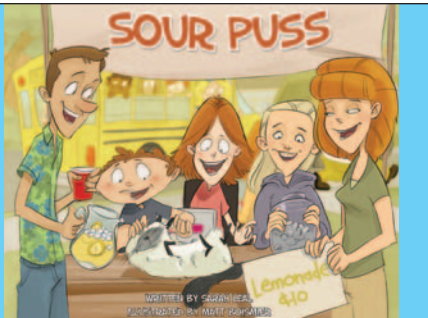


You can see then how mourning does not fully progress in a linear way, with all the steps following one another neatly in succession; it is more of a cyclical process with emotions sometimes receding only to return painfully at other times.

for survivors their life-altering experience and serve as stark reminders of the absence of loved ones. In the first year following a death milestones are particularly painful, although they tend to become easier to endure over time.



*Madi & Colin find out what happens when their mom gives up on nagging. They are free to skip school and stay up all night. What could go wrong?*



*Madi & Colin find out what happens when their mom closes the complaints department. They decide to take a turn at listening to the whining. Is it as easy as they think?*

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Consider also the pending anniversary of Gregory's death in February, which is not very far off from Christmas. An "anniversary reaction" typically occurs as the calendar date of a death approaches, with a build-up of memories of the time preceding the death, the death itself, the funeral, as well as increased longing for the person

I encourage you to offer a listening ear so that your sister can give voice to her pain. Be empathic to wherever she is currently in the mourning process. Adding to her pressures to accommodate the spoken and unspoken demands of others to get on with life will only make her more inclined to resist, while reducing your expectations

Somewhere between things being fine and things being terrible there exists a place of compromise and that is what you should be seeking under these difficult circumstances. It is quite possible that it will be a merry enough Christmas for Abby, as you and her grandparents help to shape her perspective by emphasizing what she is receiving rather than what she is missing.

## Somewhere between things being fine and things being terrible there exists a place of compromise.

who has died, all coming to mind and reviving powerful feelings of loss. The intensity of these feelings usually begins to wane once the date has passed.

Reflecting, as we have, on the complexity of the mourning process may facilitate your acceptance of your sister's feelings and your willingness to be emotionally available, particularly since her husband may seem out of reach to her as they sit on opposite ends of the seesaw.

might allow your sister to loosen some of the harsher restrictions she has imposed on the holiday. Sadly, four-year-old Abby has been absorbing the pain which has been circulating in the family and what she needs most of all are two emotionally available parents. You are right to want to normalize Christmas for her as much as possible, but only to the extent that your efforts don't create a setback by exacerbating tensions with her mother.

A final recommendation would be to honour Gregory's memory by designing and participating in a commemorative ritual as a family. You would need to suggest this idea to your sister and brother-in-law before Christmas, even though they may decide to hold the ritual closer to the anniversary of his death. Simply knowing that Gregory's life will be paid tribute may serve to assuage the hugely conflicted feelings of what it means to celebrate a holiday in the face of losing him. Having a way to channel powerful emotions through the planning and enactment of the ritual and giving concrete expression to the family's shared sadness could help to effect a sense of closure, allowing the family to heal at last. ■



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*Do you have a question to Ask the Expert? Please send all queries to Veeta Engel at [asktheexpert@exceptionalfamily.ca](mailto:asktheexpert@exceptionalfamily.ca). Confidentiality will be respected.*

**Veeta Engel** is a psychotherapist in private practice specializing in individual psychotherapy and marital and family therapy. She is a clinical member of the AAMFT and the OTSTCFQ. She is a teacher and supervisor at the Argyle Institute of Human Relations in Montreal.

# Life through an Exceptional Lens

Toronto filmmaker captures the fortitude of a family touched by **Pallister-Killian syndrome** – and zooms in on some valuable lessons for herself in the process

by LIZZ HODGSON

**A**s an undergraduate film student in the faculty of Fine Arts at York University, I recently completed my final thesis project which took the form of a documentary entitled *Welcome to Holland*. Having worked part-time for almost two years as a drama and film facilitator at Toronto's DramaWay, a company that offers creative arts programs for exceptional teens, I have always been sensitive to the challenges of people with disabilities. My experience at DramaWay, combined with an inherent passion for others' personal stories, inspired me to highlight the courage and tenacity of one exceptional family. I decided to feature the Quist family of Rochester, New York, comprised of parents Sally and Dave, and their children Bob, 10, and Todd, 7, who has both physical and cognitive special needs. What began as a quest to generate public awareness of a little known disorder became an eye-opening and life-changing experience for me.



*The Quist family: Dave, Todd, 7, Bob, 10, and Sally.*

My decision to feature the Quists was far from random; my parents are longtime friends of Sally and Dave, and through the years, they would recount many stories filled with admiration for the manner in which Sally and Dave have dealt with the triumphs around their exceptional son, Todd. In 2003 at the age of 13 months, Todd was diagnosed with Pallister-Killian syndrome (PKS), an extremely rare, genetic disorder characterized by varying degrees of cognitive and developmental delays, low muscle tone, epilepsy and distinct facial features, including widely-spaced eyes, a high forehead and an arched palate. People with PKS may also be born with heart defects, visual impairments and

deafness, among other problems. There are roughly 200 recorded cases of PKS in the world, and the syndrome affects a small percentage of North Americans. Although he can feed himself with a spoon, Todd is unable to walk, sit upright independently or speak, and has limited vision and hearing. I knew Sally and Dave were climbing their own personal mountain and I wanted to showcase their exemplary accomplishments to others.

Despite my parents' close relationship with Sally and Dave, I had never formally met them. This made the prospect of contacting them somewhat nerve-wracking, particularly since I would be asking them to

surrender their privacy and let me follow them around annoyingly with a camera for days on end, during their most intimate moments. The Quists met my request, however, with warmth and interest, eager to generate awareness about PKS and the amazing support network they had come across as a family.

## A successful shoot

I arranged for our film crew to document the family on two consecutive three-day occasions. As my excitement mounted during the preproduction phase, I promised myself that I would stay true to my role as filmmaker, and approach the project with professionalism and neutrality. During the actual shooting, however, my mind often raced with emotions and questions relating to all that I observed. The Quists were kind enough to let us capture them under various circumstances and settings: at home during meal-

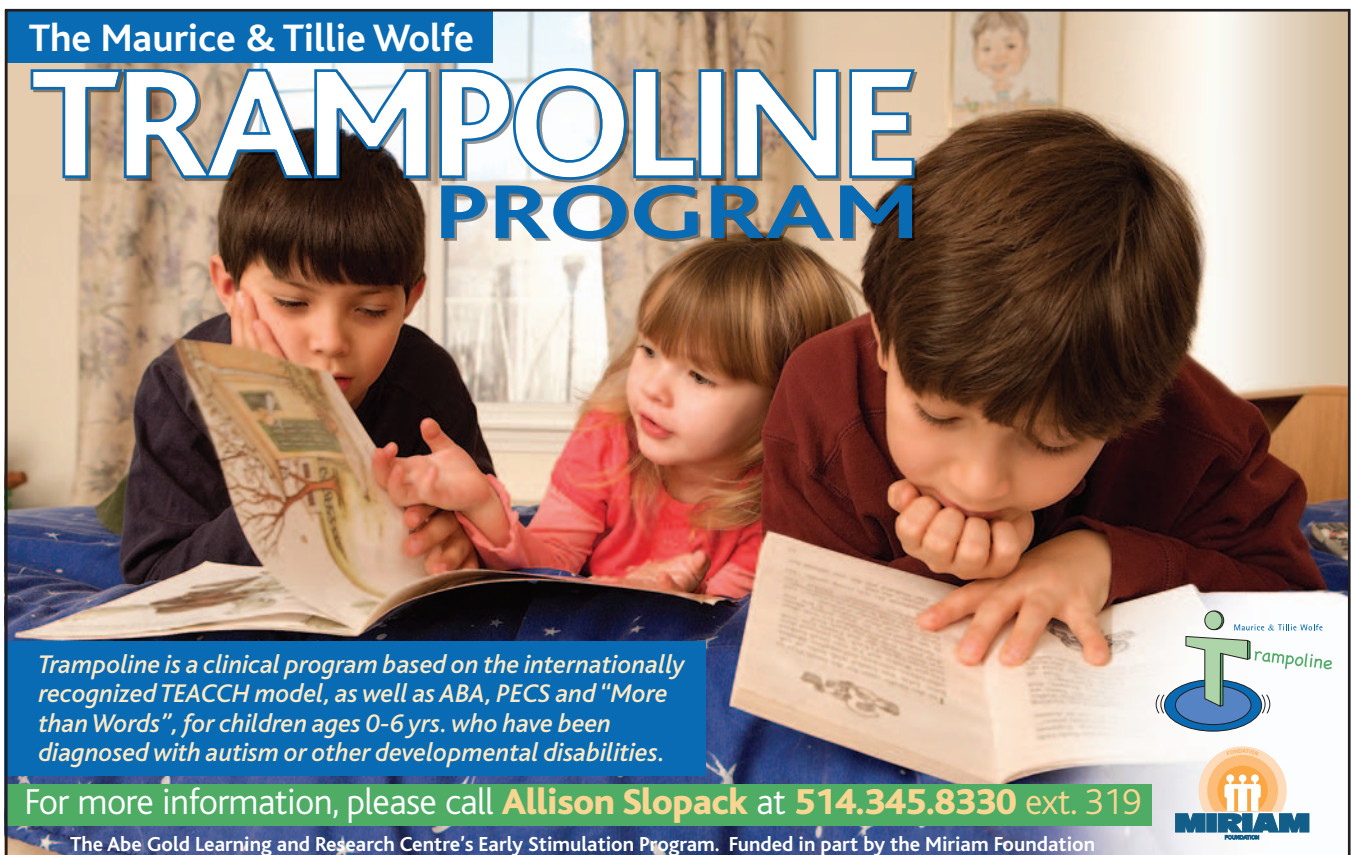
times and morning routines, at Todd's school, in the car, and at Bob's basketball game, for example.

It became clear to me early on that the Quists welcomed each new day and challenge with fresh goals and renewed hope. Despite their humility as a family that shied away from public accolades, the Quists were perpetually embraced by community members whenever we filmed outside of their home, undoubtedly the result of their infectious energy and love for one another.

I was especially touched by the family's gratitude for the "special" people in their lives, people whom Sally said she marvels at daily. I was fortunate to meet some of these extraordinary individuals firsthand, at Mary Cariola Children's Center, Todd's special school located in upstate New York. Todd has been attending Mary Cariola since he was 18 months old, and thanks to the

dedication of its remarkable staff, has learned ways to express himself through music, movement and other sensory modalities. The vital therapies he receives there have impacted Todd's quality of life tremendously. His communication has palpably improved, as has his connection with his family, friends and teachers. The center is one of the most amazing places I have ever visited. Spending hours there, I found a spirit that has helped Sally and Dave to embrace Todd's future with optimism.

I was most struck by the strength and uniqueness of each member of the Quist family – both individually and as a team. My admiration for the Quists grew with each story they shared and every trial they allowed us to record. In opening their doors to my crew and me, the Quists actively opened their hearts, allowing us to observe their most intimate moments and letting us ask questions that some of their family and friends





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may even shy away from. With each new shoot – whether we honed in on a room renovated for Todd in the Quist home, or the family car en route to Bob’s basketball game – I became increasingly aware that beyond my goal of helping to raise awareness of PKS and highlight this wonderful family, I was also embarking on a journey which put my own life into perspective and taught me that, regardless of one’s individual shortcomings, there are always things to be thankful for.

By the end of the six days, our crew had recorded about 16 hours of footage – all of which had to be edited down to a 15-minute film for the purpose of my assignment.

Since the filming of the documentary, I have visited the Quists on a couple of occasions. To witness Todd’s joyful reaction to a new presence in the room and see him physically perk up at the sound of his parents’ and brother’s voices, moves me beyond words. I cannot adequately express the degree to which my life has been enriched in making this film and connecting with the Quists. The happiness and hope that serve as this family’s foundation have impacted me greatly. I am forever in awe of those, who like Sally and Dave, who find their zest for life in their children and look forward to the future, whatever it may hold. ■

*Welcome to Holland recently won in the category of Best Documentary among five competing films at York University’s prestigious 2009 Cinesiege student festival compiled of the best documentary, fiction and alternative films produced by third and fourth year students. To view Welcome to Holland, visit [www.welcometohollandfilm.com](http://www.welcometohollandfilm.com). Contact Lizz Hodgson at [pawless-doggproductions@gmail.com](mailto:pawless-doggproductions@gmail.com). For more information on Pallister-Killian syndrome visit [www.pkskids.net](http://www.pkskids.net)*



Filmmaker Lizz Hodgson and Dave Quist help Todd to sit up.



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# Insights

A compilation of upcoming conferences and training sessions of interest

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## JANUARY

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### 12 Team Social Stories™ The Canadian Edition

#### Geneva Centre for Autism

This workshop uses lecture, demonstrations, discussion, activities, and practice of new skills to teach participants to develop Social Stories™ 10.1. Non-Members – Professionals: \$165, Parents/Students: \$145, Members – Professionals: \$150, Parents/Students: \$130. 9 am – 3:30 pm. Geneva Centre for Autism, 112 Merton Street, Toronto, ON. Info: (416) 322-7877 ext. 235 or [www.autism.net](http://www.autism.net)

### 20 Dual Diagnosis: Meeting the Mental Health Needs of Individuals with Autism Spectrum Disorders

#### Geneva Centre for Autism

Learn ways to best manage and prevent mental health crises in people with ASD and how to promote good mental health in the future. Non-Members – Professionals: \$112.50, Parent/Student: \$102.50, Members – Professionals: \$100, Parents/Students: \$87.50 6:30 – 9:00 pm. Geneva Centre for Autism, 112 Merton Street, Toronto, ON. Info: (416) 322-7877 ext. 235 or [www.autism.net](http://www.autism.net)

### 28 Advanced Communication Skills for Non-Verbal or Minimally Verbal Children

#### Geneva Centre for Autism

Learn how to assist children to use their prescribed augmentative communication systems (building vocabulary, grammar, sentence structure) and grow their communicative functions (requesting, protesting, commenting). Strategies to enhance comprehension will also be reviewed. Non-Members – Professionals \$82.50, Parents/Students \$72.50; Members – Professionals \$75, Parents/Students: \$60. 9 am – 12 pm. Geneva Centre for Autism, 112 Merton Street, Toronto, ON. Info: (416) 322-7877 ext. 235 or [www.autism.net](http://www.autism.net)

### 28 Advanced Communication Skills for Verbal Children

#### Geneva Centre for Autism

Explore ways to increase the language skills of children with ASD who are using speech as their primary form of communication but require additional support to increase their receptive and expressive language skills. Strategies to enhance comprehension will also be reviewed. Non-Members – Professionals \$82.50, Parents/Students \$72.50; Members – Professionals \$75, Parents/Students: \$60. 1 – 4 pm. Geneva Centre for Autism, 112 Merton Street, Toronto, ON. Info: (416) 322-7877 ext. 235 or [www.autism.net](http://www.autism.net)

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## FEBRUARY

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### 3 Developing Services for People with High Functioning Autism or Asperger Syndrome

#### Abe Gold Learning and Research Centre

Gain an overview of local, national and cross-country service development across educational, psycho-social and health networks. Best Practices will also be highlighted. Professionals: \$50, Parents: \$30. 7-9 pm. Miriam Foundation, 8160 Royden, T.M.R., QC. Info: (514) 345-8330 x319, or [www.goldlearningcentre.com](http://www.goldlearningcentre.com)

### 10 Working Together: The Support Worker and the Teacher

#### Abe Gold Learning and Research Centre

Learn how teachers and support workers can collaborate to facilitate better inclusion of a special child in the regular classroom. Best Practices and supports for students with special needs within the school setting will also be outlined. Professionals: \$50, Parents: \$30. 7-9 pm. Miriam Foundation, 8160 Royden, T.M.R., QC. Info: (514) 345-8330 x319, or [www.goldlearningcentre.com](http://www.goldlearningcentre.com)

### 17 Behaviour Management in the Classroom for the Support Worker

#### Abe Gold Learning and Research Centre

Learn strategies to use alongside the teacher to help manage challenging behaviours in the classroom via behaviour modification programs, intervention techniques, classroom setup, teaching styles, and creativity. Professionals: \$50, Parents: \$30. 7-9 pm. Miriam Foundation, 8160 Royden, T.M.R., QC. Info: (514) 345-8330 x319 or [www.goldlearningcentre.com](http://www.goldlearningcentre.com)

### 24 A Room of One's Own: The Role of Self- determination in Transitions

#### Abe Gold Learning and Research Centre

Self-determination and self-advocacy will be addressed with the aim of supporting exceptional people to find a place in the workforce and larger community. Professionals: \$50, Parents: \$30. 7-9 pm. Miriam Foundation, 8160 Royden, T.M.R., QC. Info: (514) 345-8330 x319 or [www.goldlearningcentre.com](http://www.goldlearningcentre.com)

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## MARCH

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### 3 Navigating Transitions in Elementary School

#### Abe Gold Learning and Research Centre

Learn practical strategies to support transitions throughout the day for young children with special needs. Topics will include alerting, scaffolding, and developmentally-appropriate self-determination. Professionals: \$50, Parents: \$30. 7-9 pm. Miriam Foundation, 8160 Royden, T.M.R., QC. Info: (514) 345-8330 x319, or [www.goldlearningcentre.com](http://www.goldlearningcentre.com)

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