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MAGAZINE FOR PARENTS
OF EXCEPTIONAL CHILDREN

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The Rise and Fall of our Exceptional Heroes



PHOTO: JULIAN HABER

More than ever, exceptional people are making headlines for their exemplary achievements and contributions to the world. Just recently our community beamed with pride upon learning that Canadian skier Brian McKeever, who is legally blind, would make history as the first winter-sport athlete to compete in both the Olympic and Paralympic Games. But that wonderful news was accompanied by some not-so-wonderful news: former marathoner Stephen Fonyo Jr., who became an Officer of the Order of Canada in 1985 after raising \$13 million for cancer research in a cross-Canada run on an artificial leg, was stripped of this honour due to “multiple criminal convictions, for which there are no outstanding appeals”, thereby undermining the prize’s credibility, according to the Rideau Hall Press Office.

News of the award’s revocation sparked reams of commentary from bloggers and journalists who rallied in protest, citing other order recipients, like Conrad Black, whose indiscretions they deem far greater than Fonyo’s, but whose memberships have been maintained. Hundreds of people joined Facebook groups demanding Fonyo’s reinstatement. Even Fonyo himself declared from prison that he deserves to keep his medal despite his actions.

The revocation of Fonyo’s award does not detract from the magnitude of his contributions both to cancer research and to the world. But being a member of the Order of Canada is a privilege that comes with ongoing responsibility. Maintaining his membership in the order would not only have legitimized his wrongful deeds, it would have also conveyed the wrong message to our children: that our decisions and behaviours are devoid of consequences.

Fonyo is not the first exceptional celebrity to be the subject of negative publicity (think Michael Phelps, Lise Thibault and Steven Fletcher, among others); and he likely won’t be the last. After all, as poet Alexander Pope noted, “To err, is human”, and we are all fallible.

For members of the exceptional community, the Fonyo incident understandably touches a raw nerve. Our exceptional heroes are more than just community representatives; they embody our hopes and dreams, personify our veiled imperfections and symbolize the potential of our special children. And though it is tremendously disappointing that one of our ambassadors has fallen off his pedestal, we as a community have always asked to be treated as equals by the rest of society and not to be singled out or treated differently. Likewise in Fonyo’s case; there should be no exceptions.

Aviva

Aviva Engel
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Bringing Up Baby

Life after the diagnosis



Exceptional dad Alex Spyridakis and his baby girl, 23-month-old Rachel.

by JOHANNA DONOVAN

"It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills.... and Holland has tulips. Holland even has Rembrandts."

- Excerpt from "Welcome to Holland", by Emily Perl Kingsley

A few days after the birth of his daughter Rachel, Alex Spyridakis of Burlington, Ontario, taped the renowned essay "Welcome to Holland" next to her hospital crib. "It got us into a positive headspace," said Alex's wife, Heather Wray, about the poem, which they had received from a friend shortly after Rachel was born.

Unfamiliar with the idea and experience of having an exceptional child, the poem helped Rachel's parents cope with their new reality. Composed by Emily Perl Kingsley, herself the mother of a child with Down syndrome, "Welcome to Holland" is a metaphor that explores the expectations and excitement of having a baby – similar to planning a trip to Italy – and the reality of discovering and coping with the fact that one's child was born with a disability – landing instead in Holland.

"When [Rachel] was born, she didn't look healthy," said Alex. "[But] I had no clue [that she had a disability]. I just thought we had a little baby who was born with some health problems."

Rachel was born at 39 weeks on April 15, 2008, blue and in distress, her mother said. Though the pediatrician pronounced her diagnosis right away, the family waited three weeks for the official results from a genetic test to confirm that Rachel had Down syndrome. "It's funny because, even though we didn't have any indication that there was

something different, I wasn't that surprised," said Heather, who "did not hold out any belief that [the test] would be negative, having seen Rachel's features for ourselves. I was kind of numb [when we got the official diagnosis]."

Already a mother to Rachel's now five-year-old brother, Adam, Heather had noticed during the pregnancy

feeding tube. During the first four days, as Heather recovered from her planned cesarean, Alex went back and forth between hospitals, visiting Rachel while his wife slept. Those days alone in the hospital without her baby were the most difficult for Heather – up all night hearing other families' exclamations of "it's a boy!" while not knowing what was happening with her own daughter.



Heather Wray sees her daughter Rachel as a gift.

“Even though she has these special needs, she’s not a demanding child. I’m well rested.”

that "the baby didn't move a whole lot." But while she was not completely surprised, her husband was shocked. "I felt like I was going to faint," said Alex, remembering vividly when the pediatrician gave him the news. "It was a huge, devastating blow."

Soon after her delivery, Rachel was transferred to the neonatal intensive care unit at the children's hospital in Hamilton. She was placed on oxygen for two weeks, and was also hooked up to IVs, monitors and a

Rachel would remain in hospital for a month, "a period of confusion and chaos", her mother recalled. The separation of those first four days – critical to mother-baby bonding – coupled with difficulties in breastfeeding and numerous tubes impeding Heather from naturally caressing and embracing her daughter, made connecting with Rachel difficult. "It was upsetting because I felt it wasn't supposed to go like this... it felt really hard to do what I needed to do," she said.

Transitioning to home life

The normalcy and routine of caring for Rachel at home, however, helped solidify the bond between mother and daughter, and a very happy new-baby period ensued. Rachel's good-natured, gentle personality and the fact that she is Heather's second child made it easier, in some ways, to be her parent. "Even though she has these special needs, she's not a demanding child. I'm well rested," said Heather.

During that first month, Heather and Alex tried to keep young Adam's schedule as regular as possible, though he did act out a little during the initial weeks when his mother was not as available to him. Today, although Adam doesn't fully understand that Rachel has a disability, he occasionally comments on the difference between her and other babies. He was surprised to learn, for example, that other newborns are brought home much sooner after birth. Still, Adam loves his sister and even "acts like a third parent," teaching her words and holding things out for her to grab. "He's her biggest fan," said Heather.

The couple had to deal with the fact that some initial reactions to Rachel were cautious. "It made me sad that people weren't happy [Rachel] was born," said Heather, who soon realized that others would take cues from her and her husband on how to approach the situation. "If you're always getting condolences for the birth of your daughter, you'll be depressed," said Alex. To break the news to friends, family and coworkers, and to highlight their optimism, Heather composed an email in which she attached Kingsley's essay and expressed her anticipation to discover Holland, having already been to Italy.



Big brother Adam, 5, is Rachel's "biggest fan".

Yet for some of Heather and Alex's family members and friends, news of Rachel's disability came as a painful shock. After learning of Rachel's diagnosis over the phone shortly after the birth, Rachel's grandmother, Jennifer Wray, hung up and burst into tears. "I was not crying for Rachel," she said. "I was crying for Heather." Going to bed feeling "beaten up," Jennifer and her husband woke the next morning determined to do their job as grandparents. On seeing Rachel for the first time in her incubator, however, all Jennifer felt was "poor little girl." Cheerful congratulations from the nurses were a bit difficult to swallow. But with a little time, reflection, and witnessing her daughter's and son-in-law's bravery, Jennifer began to view Rachel's diagnosis as a blessing. "I'm humbled by what I see in my daughter and her husband," said Jennifer. "Their strength, maturity, compassion and connection to others who are in a similar situation... it just makes me so hopeful for Rachel's future."

Reaching out

With the help of a solid support system – comprised of family members, Rachel's pediatrician, and fellow exceptional families connected

with the Halton Down Syndrome Association, which the hospital social worker had pointed her to – things became easier. Heather spoke with a counselor to confront her feelings around Rachel's diagnosis, and while she still sometimes experiences dips in her mood or is frustrated at having to visit so many medical specialists, these emotions are more tied to her own worries than they are to Rachel, she said.

Though they know there are challenges ahead and have looked into things like the Registered Disabilities Savings Plan, the family is largely focused on the here and now. Young Adam becomes more open-minded as he grows. With a developing respect for people with Down syndrome whom she regularly meets at the library where she works, Heather cannot help but feel hopeful for the future. She is confident that there is





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a place for her daughter in society and that people will ultimately come to embrace her as “Rachel”, not “Rachel with Down syndrome”. Alex has come to appreciate that his family is no more “chaotic” than any other with two young children, and now feels that “being devastated [initially about Rachel’s diagnosis] was not the right [reaction].”

Today, other than the discovery of a hole in Rachel’s heart that will only be operable in a few years, and the slew of appointments around her needs including check-ups and occupational therapy, Rachel is healthy and happy. She is behind other babies her age developmentally, according to Alex, but the family has learned to measure Rachel’s successes against her own barometer, rather than comparing her to other children.

“It’s strange to get the diagnosis before you know the baby,” said Heather. At first, all she knew about Rachel “was that she had Down syndrome – just a label.” But getting to know Rachel and others with Down syndrome, “you don’t think of them as that label,” she said. “You don’t see Down syndrome anymore.” Heather cannot stress enough what a gift Rachel is to the family. “I feel so lucky to have her in my life,” she said. “We have learned so much. [Rachel] has made us better people and more understanding of others.”

Miles apart, in it together

Only a few months after Rachel was born, another family, the Gravelines of Halifax, Nova Scotia, discovered they too would be “landing in Holland”. Leo Graveline was born on July 9, 2008, the youngest of three. His father, Major Jason Graveline, was serving in Afghanistan during most of wife Julie’s pregnancy, but



Exceptional sibs Olivia, 7, and Ethan, 9, love to dote on 20-month-old Leo.

“There was no doubt in our minds. It was: this baby’s coming and it’s up to us to change our lifestyle.”

the couple stayed in constant contact through Skype.

“Officially we found out [that he had Down syndrome] after he was born,” said Julie, but pre-natal tests revealed that Leo’s chances of having the disorder were higher than average. Undaunted, both parents researched how best to prepare for the baby they would soon welcome

into the world. “There was no doubt in our minds,” said Jason. “It was: we’ll just get on with it, this baby’s coming and it’s up to us to change our lifestyle.”

During her research, Julie was disappointed to discover that, without a definitive diagnosis, she had little access to hospital resources. “Nobody would answer my questions,” she said.

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"I didn't have a problem; I just wanted to know what our life was going to be like."

In order to be of full support to his wife, Jason requested to finish his deployment early, so that he could be present for the baby's birth. He arrived home 10 days before Leo was born. "I had very little time to struggle with [the diagnosis] and deal with it," he said, describing how he quickly tried to "get up to speed" on what Down syndrome meant.

A fetal echocardiogram failed to reveal any heart problems and after a "pretty standard" delivery, everything seemed fine. But the next day, Julie was surprised and scared to find out that Leo actually had three heart defects. "That was the biggest shock for me, when the cardiologist said we found this [with Leo's heart]... and this... and this..."

Welcoming support

Leo remained in hospital for a week, where he was treated for jaundice and feeding issues but did not need immediate surgery. In his first year,



Julie Graveline sometimes loses Leo in a crowd of church congregants who long to hold him.

though, he would have one open-heart operation and two bowel surgeries. Dealing with Leo's health problems during that period was a challenge, but family flew in to help out with siblings Olivia, now nine, and Ethan, seven. "Everyone rallied to our support," said Jason. "It was great to be able to count on [family]," added Julie. "It was stressful for us, so it was nice to have someone focusing on [Olivia and Ethan]."

The couple wanted Olivia and Ethan to get to know their little brother

first, before slowly introducing and discussing his health issues. The siblings are "totally in love" with Leo, said their mother, and often "need to be fended off [of him] in their exuberance!" They also express concern around Leo's well-being, in light of his frequent hospital visits.

"I love him just as I would any other brother," said Olivia, as Ethan pointed out that "he's very very cute!"

The older Graveline children attend a monthly program called Super Sibs, which is geared for the brothers and sisters of children with special needs. There they participate in group discussions relating to issues affecting exceptional siblings, listen to disability-themed stories, and complete crafts projects that "are completely unrelated to special needs," said Julie. "The [program] is just for them. It has nothing to do with Leo." Last year, Julie and Leo also participated in the "Roots of Empathy" program at Olivia's school. Aimed at promoting empathy and reducing peer aggression in school, the program invites a parent and infant into the classroom and encourages youngsters to observe the parent's positive interactions with his or her baby. "It was great for [Olivia] to see all those kids loving her brother," said Julie.

Very soon after his birth, the Gravelines introduced Leo to their church congregation. Jason and Julie brought him to the pulpit and read "Welcome to Holland," and invited everyone to meet their new addition. According to Julie, they wanted to show people that they

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?

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were not that upset or sorry that their son had Down syndrome, nor should others be. "We wanted the [members] to hear it straight from us."

Parishioner Elna Siebring, a respite care worker for families who have children with disabilities, offered the Gravelines friendship and help in the form of her "famous" casserole and oatmeal cookies. After discovering that Olivia and Ethan go along to many of Leo's appointments, she also offered to look after



"It doesn't matter that he has Down syndrome. He's just plain old Leo," says dad, Jason.

"I waited to burst out in tears and lose it, but it never happened. After a year, well, I don't think it's going to happen."

them so Julie could focus on Leo. "It's hard to be in a place where we need help," said Siebring. "People should reach out in practical ways and encourage [exceptional] families to reach out [for support]."

The congregation had been through the grief of losing a child with Down syndrome around 10 years earlier. As a result, Leo has been embraced with open arms, so much so that his mother sometimes loses him in the crowd of people who want to hold him.

Embracing the future

There has been little grieving in the Graveline household. "I waited to burst out in tears and lose it, but it never happened," said Julie. "After a year, well, I don't think it's going to happen." For her, the hardest things to deal with are the medical interventions Leo must undergo. "I've had moments of, 'oh, how much more does he have to go through?' I feel frustrated for him," she said. But as for the Down syndrome itself, "it's the least we have to worry about."

The Gravelines are not naive to the challenges ahead as an exceptional family – including a potential move as part of being a military family. Still, they say Leo has brought, and continues to bring, them and their community the "wonders of Holland," revealing the potential of all children with Down syndrome. Julie hopes to spread this message, in light of an upsetting statistic she came across which revealed that many pregnancies are terminated following a prenatal diagnosis of Down syndrome.²

Though they did not know anyone with Down syndrome before Leo, and the diagnosis was a big unknown, the Gravelines discovered that he is a baby just like any other. Holding Leo with his head resting under her chin is "the best feeling in the world," Julie said. "It doesn't matter that he has Down syndrome. He's just plain old Leo," said Jason. "He makes noise, he fills the diapers... Down syndrome doesn't factor in unless we're dealing with one of his issues."

Leo is the child that completes the Graveline family picture, his father said. "I can't imagine our family without him." ■

² www.ncbi.nlm.nih.gov/pubmed/10521836

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No Shame in Stuttering

How a career and a sense of self were born out of one woman's determination to conquer her speech impairment

by LEETAL CUPERMAN, MA, CCC-SLP

I was diagnosed at the age of five with stuttering. Although my parents sought treatment for me with a speech-language pathologist when I entered elementary school, I did not attend therapy consistently because of the financial costs involved¹, and my lack of availability due to school and extra-curricular commitments at the time.

As a child I was afraid to read aloud in the classroom. While some of my teachers were sensitive to my discomfort and did not call on me, others were less inclined to make an exception on my behalf. In such situations, I remember my heart pounding with fear as we went around the classroom reading and my turn approached. Once it was over, if my stuttering had been apparent, I would inevitably feel tension in my throat and chest, and

of course shame that I had somehow “failed” at the task.

In high school, despite my perpetual desire to star in school plays, I was always too scared to try out because of my speech; scared of embarrassing myself if I stuttered in public, and of looking bad in the eyes of the people watching me. I was lucky though, because I was rarely teased by my peers – something I attribute both to my friends' compassion and the fact that my stuttering was relatively mild in comparison to that of others with the same condition.

Everything changed for me when I turned 20. While in university, I learned about an intensive treatment course for adults who stutter, offered by The Stuttering Treatment Clinic at the Royal Ottawa Hospital. At the time, I resolved: “This is it! It's time to deal with this, and see it through to the end.”

And that was what I did. Given that I only began intensive speech therapy as an adult, however, the intervention I sought at the clinic was not meant to be “curative”. Rather, its goal was to provide tools to help individuals who have been stuttering for years to take control of their communication and decrease the severity of their stuttering.

Not only was the course instrumental in teaching me ways to speak more fluently and be a confident communicator, it also inspired me to enter into my current profession – that of speech-language pathologist. I now work with children and teenagers who stutter, and I love what I do!

What is stuttering?

Stuttering is when fluency of speech is impaired. The moments of stuttering are referred to as *dysfluencies*. There are different types of dysfluencies.

¹ Today, most speech-language pathology services are subsidized. Since there are waiting lists for services, sometimes families still choose to seek treatment via the private sector.

They can be repetitions of sounds (“I am c-c-c-c-cold”), prolongations (“mmmmmmom”), or blocks where no sound comes out at all as the person tries to get the word out (“I.....am cold”).

Stuttering often emerges between the ages of two and five, usually at the same time that language develops. It is genetic in 60% of cases; that is, 60% of people who stutter have someone else in their family who also stutters. In my case, my younger brother stutters, and my mother and uncle both stuttered as children. The ratio of boys to girls who stutter is 4:1. Physically, stuttering is a problem in coordinating breathing (respiration) with turning on the voice (phonation) and pronouncing sounds (articulation). While stuttering can be exacerbated or triggered by external factors such as fatigue, stress, nervousness, feeling rushed, angry, or upset, it is *not* caused by personality factors such as shyness or nervousness or “thinking too fast.”

Different people will stutter differently, and sometimes one person’s stuttering may change with time. Occasionally, other involuntary behaviours may also manifest as a person’s body reacts to release the tension associated with stuttering. These *secondary behaviours* may include not making eye contact

when stuttering, hitting one’s leg to get a word out, or locking one’s jaw. People who have stuttered for a long time may also exhibit *avoidance behaviours*, such as steering clear of certain words known to cause them to stutter. Some may even go so far as to avoid certain people, situations or careers that may prove stressful and induce their stuttering.

If your child has been stuttering for more than six months, consult your pediatrician and request a referral to a child rehabilitation centre in your area. The Canadian Association of Speech-Language Pathologists and Audiologists website may help you to locate a SLP in your area: go to www.caslpa.ca and click on “Consumers” then “Find a professional”.

When I stutter, I avoid eye contact with the person with whom I’m interacting. Once in a while I also catch



Speech-language pathologist Leetal Cuperman is “grateful to be someone who stutters”.

myself avoiding a certain word, when I am convinced I will stutter on it. Because of my training and awareness of my disorder, I usually say the word I intended to use anyway, and employ one of the many strategies I know to help convey it fluently.

Though my stuttering problem is now quite mild, I still find it stressful during work-related meetings, for example, when having to introduce myself to colleagues in a round-table setting. I am also not fond of introducing one person to another, because I feel pressured to say people’s names quickly. Despite these stressors, however, my life is not defined by my stuttering. I view it as another challenge that I have to deal with and work on, like losing weight would be for someone else, for example. In fact, I would even go as far to say that I am grateful to be someone who stutters, because my disorder led me to my rewarding

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career – one that enables me to help and encourage youth who have been diagnosed with the same condition as my own.

The following tips² for parents and educators of children who stutter may prove helpful:

1 Be a good listener. Get down to your child's level, make eye contact and let your child finish sentences – avoid supplying missing words. Listen to *what* your child says, not *how* he says it. Avoid saying things like: "Take your time" or "Think about what you are going to say before speaking." These statements imply that correcting a stutter is easy to do on one's own, when in fact, it necessitates careful therapy planning from a trained speech-language pathologist. Such statements

may also increase a child's self-consciousness and stress level, and actually exacerbate the problem.

2 Explain to your child if you are in a rush and don't have time to wait for her answer. Assure your child that you will talk to her as soon as you are available, so that you can hear what she has to say. This way, your child can communicate her message in a context where you have significant time and she won't feel rushed.

3 When talking to your child use a slow model of speech. Sometimes speaking more quickly can increase stuttering. If you take your time, he will too.

4 It's normal to have good and bad days. If your child is having a good day, give him



lots of opportunities to talk (e.g., by playing with puppets, or describing pictures). If he is having a bad day, engage him in more non-verbal activities to take the pressure off.

² Tips taken from the "Stuttering" booklet compiled by the Speech and Language Department at the Montreal Children's Hospital, McGill University Health Centre.

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5 If your child is younger than five, expect that she will naturally make mistakes in grammar or pronunciation. Avoid having her repeat the message if you understood it. If you wish to correct your child for future reference, simply repeat the message back in the correct form.

6 If you have more than one child, establish turn-taking rules to be respected by all family members (i.e. first I speak, then you speak). A situation where people are cutting each other off may create more pressure for your child to speak quickly in order to get a word in; this can increase stuttering.

7 If your child is concerned about his speech, reassure him that there are many times that he speaks well. Emphasize that we all have little bumps in our speech sometimes.

Finally, to all parents of children who stutter, don't panic! According to Ehud Yairi, a world-renowned

stuttering expert, 45-80% of all individuals who stutter will spontaneously recover, with or without therapy. However, if one's stuttering persists beyond six months, experts strongly recommend that it be treated as soon as possible. The "wait and see" approach is therefore inadvisable. The sooner you treat the stuttering, the easier it is to treat. While the

chances that the treatment will be successful are also greater with early intervention, speech therapy for older children and teens who stutter has also proven extremely effective in minimizing stuttering and equipping participants with tools to become confident communicators. I am living proof of speech therapy's effectiveness, after 15 years of stuttering. And if I was able to move on to a successful career and happy life despite my occasional trouble getting a word out – anyone can! ■

To speak with Leetal Cuperman about stuttering, contact her at leetal.cuperman@muhc.mcgill.ca

Leetal Cuperman, MA, CCC-SLP, has been working as a speech-language pathologist for seven years. She currently works at the Montreal Children's Hospital, the Jewish Rehabilitation Hospital, and in private practice. Her specialties include stuttering and early childhood language.

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Ask the Expert



PHOTO: LAWRENCE CLEMEN

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

An adult sibling reflects on her painful past

Q I'm the 36-year-old mom of a "typical" 7-year-old girl. My older sister Kelly, who is four years my senior, had meningitis as an infant and was diagnosed with mild retardation as a toddler. Growing up, I became the older sibling, and everything revolved around Kelly's needs. I can still hear my parents' perpetual refrain when introducing her to strangers: "Kelly was a very sick baby". I was never allowed to host sleepovers because I was told that too many people and too much noise in the house would overwhelm her. Going to restaurants as a family was out of the question, as were outings to the zoo or amusement park. When all of my friends went to sleep-away camp, I stayed home as my parents said the money was needed for Kelly's therapy. The other day I was pushing my daughter on a swing in the park and it dawned on me that when I was her age, I would perpetually go to the park alone. No one was there to push me, or praise my efforts on the monkey bars. I even recall many nights when no one was available to tuck me in to bed.

I can't get these childhood flashbacks out of my mind. I feel increasing resentment toward my parents for neglecting me the way they did. I wonder if they even realize the degree to which I was deprived and left to fend for myself. I want to confront them about it and ask why they chose to have a second child when they knew the first one would take up all of their time and energy. Do you think I should?

A There is little that is as disheartening as finding yourself well along the journey of life only to get dragged down by heavy baggage from your past. You question whether you should confront your parents about their inability to meet your childhood needs. But, I think your question really implies a search for guidance to lighten your emotional load, a commendable and most necessary goal.



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The impulse to put the blame back onto one's parents for what is felt to be their past wrongdoings is a common one. It presumes that in holding them accountable there will be a confession on their part, validation of the hurt inflicted, and apologies forthcoming. It doesn't factor in the possibility that they may have vastly different recollections from your own or that they may attribute different meanings to the very same events.

It is not unusual in exceptional families for typical children to be perceived by their parents as more self-sufficient and less demanding than they really are.

You describe a sense of growing up in the shadow of a sister with special needs and feeling that you were so insignificant in your parents' eyes that they must have been thoughtless, careless, or selfish in bringing you into the world – an outlook which has filled you with bitterness and resentment.

Ask the Expert

It is not unusual in exceptional families for typical children to be perceived by their parents as more self-sufficient and less demanding than they really are. This happens for a variety of reasons: firstly, because the perception is true relative to the needs of the exceptional child for care and attention, and second, because parents (consciously or unconsciously) feel responsible for causing the special

needs condition and thus compelled to make amends by redoubling their efforts toward the most vulnerable of their children. Typical children, in turn, tend to comply unconsciously with the expectation to have minimal needs, which explains why you are only responding to your feelings in the here-and-now as they are being called up through your relationship with your own child.

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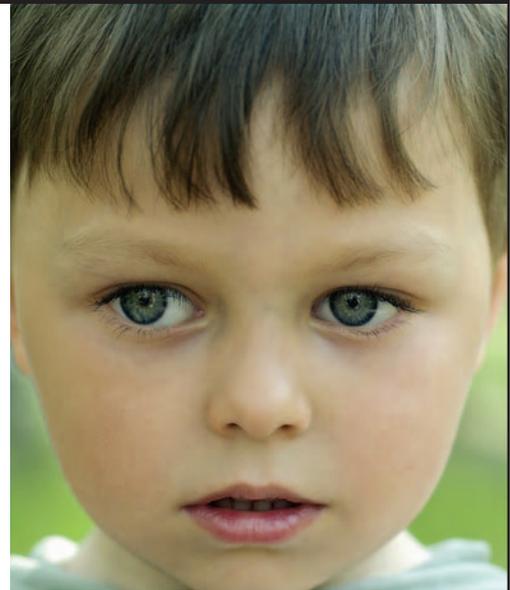
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The Simons Foundation is a philanthropic organization that funds the Simons Simplex Collection and other autism research. Learn more at www.sfari.org

Ask the Expert

As you can see, this has nothing per se to do with not having been wanted and loved by your parents, but more likely to do with a family

too emotionally overwhelmed to focus on any of the normalizing aspects of family life. If the clock could be turned back,

If the clock could be turned back, yours would have been a family that could have benefited tremendously from family therapy.

dynamic in which everyone including you would have colluded to make sacrifices for the sake of your exceptional sister.

Although this insight might assuage some of your feelings of rejection, sadly, as you convey, the sacrifices you endured were great – perhaps far greater than may have been warranted. If the justification for the family to forego recreational outings, visits to restaurants, etcetera, was based on your sister's mild retardation, it invites speculation about your parents' own states of mind. Perhaps they felt too ashamed, depressed, or altogether

yours would have been a family that could have benefited tremendously from family therapy, which was just beginning to gain momentum around the time you were a child.

This brings me to my recommendation that you seek some individual therapy for yourself. Revisiting your childhood pain by confronting your parents will do little if anything to help you overcome the hurt you feel and would more likely stir up fresh hostilities compounding your existing pain.

Therapy will help you let go of your wish to seek retribution for the

suffering you experienced, enabling you instead to assume adult responsibility for your emotional well-being. You will be supported to gradually unpack the baggage which has begun to weigh you down, and encouraged to sort through, discard and reorder the painful contents of your past, freeing you up to continue on the journey of life. ■

Do you have a question to Ask the Expert? Please send all queries to Veeta Engel at 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.



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PHOTO: JULIAN HABER

Eleven-year-old Kenny Eekhor and his parents Charlene Gardner and Kenneth Eekhor have nothing but praise for the Childhood Disorders Day Hospital at Montreal's Jewish General.

A PLACE FOR US

Families coping with mental health issues and severe behaviour challenges find hope and support at multimodal treatment centre

by STEWART LAZARUS

For many parents of children with psychiatric disorders and/or severe behaviour challenges, life can often be overwhelming. The thought of discussing and treating the various issues that accompany their children's diagnoses can also be tremendously anxiety-provoking. While some parents may not know where to begin in terms of finding the best treatment model, others are discouraged by the length of the process. Some may not have seen the desired results in other settings and are therefore reluctant to try a different intervention. Many parents also fear they will not have a say in the treatment, while others worry that they may be blamed for their children's issues. Then there are those who have consistently been told that their son's or daughter's cases are "hopeless".

Thanks to a one-of-a-kind program at Montreal's Jewish General Hospital

(JGH), however, numerous parents are finding renewed strength and reasons to be optimistic about their children's futures. The Childhood Disorders Day Hospital offers a unique approach to child psychiatry by directly supporting parents and families and easing the treatment process both for the child and those closest to him or her. "We always involve parents at every step of their child's treatment," says Dr. Jaswant Guzder, Head of the Day Hospital. "Many of the children and parents come from different backgrounds. It is therefore crucial that our staff is welcoming to all and shows cultural sensitivity." Guzder understands that the decision to seek treatment for their children is not an easy one for many parents, and she commends them "for their great courage and strength to become actively engaged in the treatment process."

The Day Hospital is designed for children ages seven through 12 who are unable to function in their communities due to serious psychological, cognitive, behavioural and/or family problems. The program can accommodate 28 children, and the majority of those enrolled attend their regular elementary schools concurrently. Children are accepted from all school boards, both on and off the island of Montreal. The average length of treatment is six to 12 months, with “graduation” from the program being the primary objective.

Teamwork as a foundation

Whereas other treatment programs may isolate and target specific behavioural issues independently, a distinct feature of the Day Hospital is its multimodal treatment philosophy. From psychiatrists and occupational therapists to psychologists, social workers, art therapists, and childcare workers, all specialists involved in a child’s treatment work collaboratively with families to effect positive outcomes.

“In the beginning, each child is assigned a primary care worker to work with them and their families,” says Esther Watts, herself a Day Hospital primary care worker. Watts oversees a child’s progress and is in constant communication with his or her parents. “Eventually the child



PHOTO: JULIAN HABER

The Day Treatment team (back row from left): OT Carine Zekry, special ed teachers Eva Feil and Jodi Belik, childcare worker Stephen Hennessy, nurse Vincy Pulickakudyil and triage secretary Nichol Roach. Front row from left: head nurse Rosemary Short and childcare workers Joe Della Cioppa and Esther Watts.

gets to know the entire team and develops positive relationships with everyone involved.”

Many children in the program experience extreme academic and social difficulties in their schools because of diagnoses like ADHD, defiant conduct disorders, or other conditions, like autism and learning disabilities. From honing participants’ social and language skills and helping them with anger management, to teaching them how to ask for help and interact with peers, Guzder explains that the program is competency-driven, aimed at training children “to function successfully in their communities, both at work and in play.”

As Watts relates, program educators sometimes even turn children’s occasional negative life experiences into opportunities to teach them critical life lessons. “Many children in the program [have been] labeled as “bad” or “problems” by their schools. It is important for these children to evaluate how and why they have earned these unfair reputations and how they can go about reversing them,” says Watts, who underscores that the concept of a “reputation” is one that is thoroughly explored with children.

Parental involvement is paramount

Referrals to the program are made directly by parents themselves, not from outside agencies. Requests for consultations are accepted year-round, though the programs operate from September to June. For the entire Day Hospital team, the active participation of parents in their children’s therapy is critical. All parents and children must agree to attend one-on-one weekly sessions with a therapist. Siblings and anyone else residing “under the same roof”



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are also required to undergo therapy, says Watts. Other relatives, such as grandparents, are invited to attend as well. "The involvement of family members is integral to the wellbeing of the child and to the overall success of the program," says Guzder. "By involving the parents, the child realizes the strong support system for him or her. As well, once the parents are involved,

Both Kenny and his parents were very satisfied with the program. Through occupational therapy, Kenny's writing improved and he even learned to ride a bike. Kenny also enjoyed family therapy, and would "run down the halls, sharing his excitement and eagerness" when it came time to participate. Gardner adds that Kenny was particularly enthusiastic about the program's camping and zip-lining

are addressed immediately at the Day Hospital and that parents and extended family are always warmly received. Gardner agrees, saying, "When I first walked into the hospital I immediately felt welcome and at home."

The JGH's child psychiatry department will soon relocate to a brand new building, slated to open this spring. The site will enable the integration of more services and will boast state-of-the-art facilities including a gym for physiotherapy and sports, and a music therapy room, all essential to the children's wellbeing and development. A resource centre with services and support for parents is also in the works.

The child psychiatry teams hope the inauguration of the new building will help to legitimize the field of child psychiatry in the eyes of the public, diminish the stigma associated with mental illness and facilitate links and relationships with other local resources. The fact that it was largely financed by generous community-wide donations suggests to Guzder that people are increasingly gaining an awareness of, and appreciation for, the field of child psychiatry and the importance of proper treatment for related disorders. More than a symbol of hope, it will surely enable the department to achieve its goal of putting the valuable work of the Childhood Disorders Day Hospital "on the map." ■

In addition to the Childhood Disorders Day Hospital, the JGH Child Psychiatry Department offers several multimodal treatment programs for children ages 4-7, and evening programs for children ages 6-12 who function relatively well in school but require additional support around anxiety, social skills challenges or ADHD. For more information on any of these programs, call (514)340-8222 ext. 5629.



PHOTO: JULIAN HABER

Kenny and his special ed teacher, Jodi Belik.

they realize that their children's [condition] is nothing to fear and that their children can still lead fulfilling lives."

Montreal mom Charlene Gardner was eager to become involved with her 11-year-old son Kenny Eekhor's treatment at the Day Hospital. Kenny had exhibited behavioural problems in his school which impeded the development of positive relationships with his peers and teachers. The school's approach to disciplining Kenny would be to dismiss him whenever he acted out. "Kenny would become accustomed to being sent home early each day," says Gardner. "My husband and I realized we needed a different treatment model."

outings. Kenny recently celebrated his graduation and has returned to school full-time where he is thriving.

Erasing the stigma

While Kenny and his parents experienced success with the Day Hospital program, Guzder is aware that many mothers and fathers are reluctant to seek proper treatment for their children because of the stigma associated with mental health issues. "Many parents suffer from the negative stigma. They fear that their children's conditions will never improve, so they avoid all types of treatment." She notes, however, that parents' worries that they will not have a say in their child's treatment, or that they will be blamed for their child's condition,

Kids' clumsiness linked to a disorder

Approximately six percent of children who are generally considered clumsy and uncoordinated actually live with some form of a condition called developmental coordination disorder (DCD), research out of the University of British Columbia reveals. As reported by the Canadian Broadcasting Corporation, UBC researchers analyzed brain scans of children who struggle to write, use scissors, tie their shoelaces or play sports, and found that they "are not activating the same brain areas as typically developing children," according to Jill Zwicker, researcher and PhD candidate in rehabilitation sciences at the university. While people generally assume that such children will eventually outgrow their challenges, Zwicker cautions that those with the disorder are at increased risk for depression and anxiety that can persist into adulthood. She suggests parents consider alternatives for their children who struggle, such as individual versus team sports, or computers in place of pens and pencils.



Adapted computer mouse designed with vision in mind

An increasing number of people with visual impairments may soon be able to enter the workforce, thanks to the invention of a tactile mouse geared to facilitate computer use for people who are blind. Manufactured by the Israeli company Tactile World, the mouse is fitted with two pads containing 16 pins arranged in four-by-four grids that rise



and fall to translate computer text into Braille. One pad spells out the letter or number that the cursor is on, using the pins to mimic Braille bumps, while the other pad indicates what follows - whether another letter, or the end of a word or sentence. The mouse is programmed to inform users when links to other websites appear in the text, and users may also choose to have the system read the text out loud in its entirety. According to TheEconomist.com, the tactile mouse is considered more technologically advanced and reasonably priced than other current systems for people with visual impairments; while computer-connected Braille readers cost upwards of several thousand dollars, the mouse's price tag runs just under US \$700.



Stem cell treatment holds promise for premies

A new treatment method for premature babies with underdeveloped lungs might move toward clinical trials within the next three to five years, according to CBC.ca. Thanks to funding from the Alberta Heritage Foundation for Medical Research, scientists succeeded in repairing the lungs of baby rats by injecting stem cells from bone marrow into their airways. Subsequent tests examining the rats' lung capacity found that the rodents were more likely to survive and were able to run twice as far as those that had not received the stem cells.

Often, premies born with underdeveloped lungs must be hooked up to ventilators, which can cause irreversible lung damage. Approximately 50 percent of babies born before 28 weeks develop chronic lung disease, which limits their lung capacities as they age. While the potential side effects of the stem cell treatment have yet to be determined, the discovery "offers real hope" for such infants, says Dr. Roberta Ballard, a pediatrics professor at the University of California, San Francisco.

Think your preschooler is being adequately stimulated in daycare? Think again.



Children in daycares are watching too much television and DVDs at the expense of quality play and reading time, says Dr. Dimitri Christakis, director at the Center for Child Health in Seattle and professor of pediatrics at the University of Washington. A recent study conducted by Christakis of 168 childcare centers in Florida, Massachusetts, Washington and Michigan found that 70 percent of home-based and 36 percent of center-based daycares incorporated television as part of their curricula.

The average American toddler spends about five out of 12 waking hours daily in front of a TV, either at daycare or at home. Too much television intake has been linked to shorter attention spans, child obesity and developmental issues characterized by a limited vocabulary, and a lack of imagination and school-preparedness. Exactly why there is an over-reliance on television to get kids through the day remains unclear. Possible reasons include staff shortages and lower levels of education for owners of home-based daycares. The findings were published in the journal *Pediatrics*.

Autism intervention proves effective for babies younger than two

Babies as young as 18 months who exhibit signs of autism stand to gain from early intervention aimed at diminishing their symptoms, a study out of Seattle's University of Washington (UW) reveals. Published in the journal *Pediatrics*, the five-year study marked the first controlled examination of the effectiveness of an intense behaviour program – the Early Start Denver Model – on toddlers younger than two. ESDM combines behavioural analysis teaching methods and developmental relationship-based approaches, with an emphasis on social interaction and communication.

UW researchers split 48 children between the ages of 18 and 30 months into two groups. The first participated in the ESDM for 20 hours weekly; the second joined community-based autism programs. After two years of treatment, the children in the first group had surpassed their peers in the domains of language, social interaction and IQ. Approximately 30 percent of the ESDM kids were also re-diagnosed with a milder form of autism - pervasive developmental disorder not otherwise specified (PDD-NOS).



While experts have long touted early intervention's value in diminishing the symptoms of autism, this latest study encourages parents to seek treatment for their children as soon as worrisome signs surface. In one-year-olds, such signs include no longer imitating adults or responding to their names, or showing increasing disinterest in play.

English + français + espagnol = A leg up



Exposure to multiple languages can improve cognitive function, an international study led by the European Commission shows. According to the *ScienceDaily* website, the areas where multi-

lingualism puts people at an advantage over their peers include the ability to learn in general, think creatively, problem-solve, and communicate. Although learning languages as part of a school curriculum is valuable, learning different subjects in multiple languages has an even greater effect on the brain, says David Marsh, coordinator of the research team.

While previous findings highlighted the benefits of multilingualism in improving cognitive abilities, it was believed that proficiency in the second and third language was necessary in order for brain activity to be positively altered. The current report suggests that the brain may even begin to benefit in the very early stages of language acquisition.

AN INTERESTING PARADOX:



Sign Language for Children who Hear and Speech for Children who are Deaf

by J. FREEMAN KING, Ed.D.
Utah State University

The latest phenomenon to impact North America related to language acquisition and learning is the use of sign language to enhance the language development of hearing babies, toddlers and preschoolers. Conversely, there is a push, mainly by substantive oral-aural organizations and some psychologists, audiologists, and speech language pathologists, to promote speech, but not the use of sign language, for infants, toddlers, and preschoolers who are deaf. The basis for this push is the erroneous belief that the use of sign language will inhibit, if not prevent, the development of speech. Herein is the paradox: eliciting the use of another sense (vision) and sign language to promote language

development in the hearing child, yet prohibiting the child who is deaf from using a visual language. In essence, the deaf child is being penalized for his or her weakness (hearing), instead of promoting their strength (vision).

Research has shown¹ that sign language (for both hearing and deaf infants, toddlers, and preschoolers) provides the earliest possible mode through which children can learn expressive language skills and open the door to shared meanings. The reason for this is that children begin to learn language long before they are physically capable of producing speech. While speech capabilities are still maturing, children struggle to find ways of expressing their wants, desires, and intentions. Given exposure to a visual language

of signs, children are able to master language at an earlier stage. Signing children can communicate, while their peers are frustrated when others cannot comprehend their communication attempts.

Linguistic competency is necessary for human interaction. Language is necessary for the flow of information between children; between children and their parents; and between children and their teachers. Language is used to develop and enhance cognitive skills, to develop literacy, and to develop social and emotional skills. It is the pathway to intellectual growth, and essential for involvement in the entirety of the educational experience. Hence the idea that sign language can be another avenue to assist the hearing child in learning

1 Crais, E.; Watson, L.; and Baranek, G. (2009). *Use of gesture development in profiling prelinguistic communication skills*; American Journal of Speech-Language Pathology, 18 (1), 95-108.



and utilizing language. Sign language is a tool that can be used to promote language and speech competency in hearing children, even though speech is the primary tool through which language is produced. Is it not putting the cart before the horse when speech, which either cannot be heard or only partially heard, also becomes the primary tool for the child who is deaf through which language can be accessed and produced?

If, in fact, as research has demonstrated² the use of sign language promotes speech development and provides a bridge to English language acquisition in children who can hear, would it not be logical to assume that the use of sign language by children who are deaf would also be a viable bridge to accessing the English language?

2 Bavelier, D.; Newport, E.; and Supalla, T (2003). *Children Need Natural Languages, Signed or Spoken*; The DANA Foundation Press; Cerebrum.

3 Goodwyn, S.; Acredolo, L.; and Brown, C. (2000). *Impact of symbolic gesturing on early language development*. *Journal of Nonverbal Behavior*, 24, 81-103.

4 *Educating Children with Autism* (2001); Committee on Educational Intervention for Children with Autism, National Research Council, p. 58.

Even though North American education champions bilingualism in hearing children, why does it in the same breath, apparently for the sake of parental and educational options, deny such a possibility to children who are deaf? Is it not logical and linguistically savvy to play to the child's strength and not his or her weakness?

Common sense, as well as research³ has illuminated much related to language acquisition and language learning:

Early language learning experiences affect other areas of development that are critical to children's future success. Lack of language access can negatively impact cognitive, psychological, and social development. Poor language skills are often linked to behavioral problems, academic difficulties, lowered self-esteem, and social immaturity. Behavioral problems, for example, are often the end result of children's frustration at not being able to communicate with their parents or significant others. Yet, research⁴ shows that children with strong language skills, regardless of the language, consistently outperform their peers on tests of intelligence and other measures of success. The language might be English or French or another spoken language, or it can be sign language; the key is language accessibility of a deep and meaningful nature. The earlier a child acquires his or her first language, the greater the success will be in acquiring subsequent language skills and meeting other important developmental milestones.

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with no risk to academic, social, or emotional development, or spoken language skills. For both hearing and deaf children, sign language gives a head start in language learning, and can lead to higher achievement in measures of intelligence and academic and social development. It is also important to note that there is no substantial body of research that indicates learning and using sign language will hinder the development of speech skills in either deaf or hearing children.

For infants, toddlers, and preschoolers who are deaf, sign language is a critical first step to communication. It provides the only accessible venue for natural and complete language acquisition in the early years, and serves to prevent children who are deaf from becoming victims of the staggering language delays often associated with deafness. Beyond the enormous advantages to deaf

children's language, social and cognitive development, children's knowledge of sign language opens the door for involvement with a strong and supportive community of other deaf individuals.

Infants, toddlers, and preschoolers who are hard of hearing often fall through the cracks of the educational system, because of the erroneous assumption that they are primarily auditory learners. Even minimal hearing losses that are diagnosed as being within normal limits have been shown to have significant negative impacts on children. The less significant the hearing loss, the smaller the chances of having the loss identified early. After the hearing loss is identified, technological assistance and/or added speech training are hard pressed to compensate for a profound inability to fully access spoken language. For these children, sign language

provides the only bridge to fully accessing language. It also serves to provide access to the critical element of incidental learning, in that a visual access to language is given that would otherwise be missed by assuming that the child is able to hear and understand the spoken form of the language.

Even though technology can be a useful tool for promoting speech, it does not necessarily assure the expectations espoused. A child with a cochlear implant or one who uses hearing aids is, at best, hard of hearing. Maintenance issues, programming/adjustment issues, and restrictions as to when and where technological devices can be conveniently and safely used can create problems. The use of sign language is a viable solution to these problems. Sign language can be utilized before audiological supports can be properly fitted and/or programmed for chil-



dren. If children are able to develop spoken language skills, the use of signs should be continued to complement spoken language, especially

it seems only logical to play to the child's strength, vision, and not his or her weakness, hearing.

Perhaps all children who are deaf should be placed in signing programs initially, then switched to oral-aural programs if they are failing.

when the need for communication is immediate and spoken language becomes inadequate due to difficulties with the technology, poor acoustics in the environment, or other extenuating factors.

The question, "is sign language the right choice for every child?" will naturally be raised. Certainly, only the child's family can make this decision; however, closely observing and letting the child take the lead regarding communication and language is an important element that should be considered. Regardless, keeping in mind that the child who is deaf (with or without a hearing aid or a cochlear implant) is primarily a visual learner,



Historically, many children who are deaf have been placed in oral-aural only programs, then transferred to signing programs when it was discovered that they were not oral-aural candidates, and were not able to access language. Perhaps all children who are deaf should be placed in signing programs initially, then switched to oral-aural programs if they are failing. It is safe to say that very few would be switched to oral-aural programs due to failure to access language. Initially, though, the child ought to be given the best of both worlds: the opportunity and the ability to use sign language, when appropriate, and the opportunity and the ability to use speech, when appropriate. ■

Dr. J. Freeman King is the director of Deaf Education at Utah State University. He has worked as a classroom teacher, coach, Dean of Students, and supervising teacher at the New Mexico School for the Deaf and the Louisiana School for the Deaf. Dr. King has authored numerous articles for professional journals, and two books related to Deaf Education: *Basic American Sign Language Principles for Hearing Parents of Deaf Children* and *Introduction to Deaf Education: A Deaf Perspective*. He is also the author of *Underwater Communication: A Guide for Scuba and Commercial Divers* and co-developed two poster series for classroom teachers of deaf children: *Signs with Multiple English Meanings*, and *Signonyms*.

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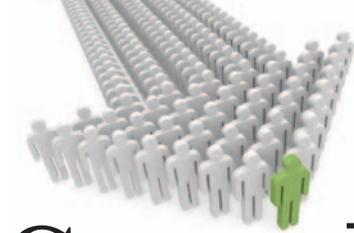
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Sure I can

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

A MATTER OF ATTITUDE:

Wheelchair racer Daniel Normandin



PHOTO: JULIAN HABER

Over the years I've been told that my ability to lead a full and rewarding life in spite of my disability serves as an example to others of the potential for people to overcome their challenges.¹ The secret behind my fulfillment, however, is actually not a secret at all; rather it's my tendency

to view the glass as half full whenever possible. Is your glass half full or half empty? Do you approach life with an optimistic perspective, or a pessimistic one?

One man who certainly approaches life with optimism is 38-year-old wheelchair racer Daniel Normandin, of Montreal. At the age of eight, Daniel was diagnosed with bone cancer and his left leg had to be amputated. Following two years of chemotherapy to fight the cancer, Daniel was okay for two years, until he learned at age 12 that the cancer had metastasized to one of his lungs. A second operation to remove a small piece of his lung and a year and a half of chemotherapy sent the cancer back into remission. It was then, at age 15, that former wheelchair marathoner and Paralympian André Viger introduced him to wheelchair sports – which very quickly became Daniel's life passion.

For Daniel, engaging in wheelchair sports was not only enjoyable, it gave him the opportunity to exercise his competitive drive. It was not enough to simply have fun; Daniel wanted to be the best. He tried out a variety of sports, including skiing, sledge hockey, water polo, spring-board diving and wheelchair basketball – a sport he played competitively from 1986 to 1995. In 1995, Daniel competed at the Canada Games² as part of the Quebec Provincial Junior Team.

At age 23, however, Daniel decided to quit competitive basketball and focus his efforts on wheelchair racing. "I realized I like to go fast, so wheelchair racing was a good sport for me," explains Daniel, who has been competing internationally since 1998. In 2005, he finished in fourth place in the 100m race at the World Championships in Helsinki, Finland. A particularly proud achievement for Daniel, however, was when he represented Canada at the Athens Paralympic Games in 2004. While he finished 16th in the 100m, and 17th in the 200m races, the greatest highlight for him was when he was picked to race the starting leg of the 4 x 100m relay race for Canada. "It was a great honour to wheel into a packed stadium and take my place on the starting line, representing Canada," says Daniel.

What makes Daniel's performance in Athens all the more impressive is that in February 2004, just eight months before the Games, a skiing accident resulted in him breaking his back. He spent one and a half months in a brace and, following intensive physical therapy, worked hard to get back into shape. Four months later, Daniel's hard work was rewarded when he got the call to join the Canadian team in Athens.

Yet the road to good health unfortunately was not smooth for Daniel. In 2006, the 35-year-old was diagnosed with thyroid cancer. Five surgeries in three years successfully beat the disease, the last operation taking place just seven weeks before the 2009 Canadian Track and Field Championships in Toronto. Daniel not only competed, he won a bronze medal in the wheelchair 100m final, followed by a fourth place finish in the 200m race a day later.

1 I was born with a condition called Multiple Congenital Musculoskeletal Abnormalities. As a result, throughout my youth I had a total of nine operations to form both left and right hip sockets, construct a functioning knee joint on the right side and correct an irregular curvature of my spine (scoliosis).

2 A tournament held every two years that brings Canadian athletes together to compete in both wheelchair and non-wheelchair events, similar to the Olympics.

Sure I can



Daniel Normandin represented Canada at the 2004 Paralympic Games in Athens.

Considering Daniel's medical history, some may question how he could possibly have kept going, all the while remaining optimistic that he would be well enough to compete. But Daniel has no time for pessimism or self pity, he says. "Never...not even for one second. I have never considered myself to be unlucky. I have had some challenges in my life but I am the luckiest

man in the world to recover as fast as I do. I am just happy to be alive and have the chance to work and have a normal life."

When he's not out on the racetrack, Daniel earns a living making prosthetics for other amputees as a Canadian Certified Prosthetist. Having always been fascinated with the workings of the human body and having an affinity for mechanics, a career in prosthetics seemed the perfect fit.

Daniel uses his own experience as a person with an amputation to help his clients deal with the emotions around getting prosthetics. "A big part of your body [may be] lost," says Daniel, "but in a while, if the person accepts the situation, life will be back to normal – or almost normal."

As for his sunny outlook on life, Daniel says, "I am who I am because of my life experiences. I cannot imagine now who I could be if I [still] had my two legs or [had] never lost my leg. It is a small handicap because I can do everything I want. There are some people who will not do everything they want to do, even with both arms and legs. It's just a question of adapting the situation to your reality. I am not afraid of anything."

In other words, Daniel truly believes he can. ■

Do you know someone who exemplifies the "Sure I Can" mindset and think their story is worth sharing? E-mail me at Michael@sureican.info.



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Understanding Shut-Down Learners

Six strategies to help your academically-discouraged child climb from struggles to success

by RICHARD SELZNICK, Ph.D.

Throughout preschool and her early elementary grades, Emma was sunny, confident, and engaged in school. Now 12 and in Grade 6, her teacher's comments paint a different picture:

Emma enters class pleasantly and she seems to get along nicely with the other kids. During class, however, Emma never participates and it seems that her mind is elsewhere. Emma's work reflects a general lack of effort. It's almost as if she doesn't care.

What happened to the sunny, confident and engaged Emma?

Jacob, age 9, loves playing with Lego and other hands-on materials. Building elaborate cities and complex scenes, he is confident and very capable. In class, though, Jacob is unenthusiastic. An observer watching Jacob's lack of connection and energy in class would probably think his "light bulb" was dim. Often, Jacob actually looks pained in class – particularly during open-ended writing assignments.



A recent sample of Jacob's writing about a school experience offers insight into Jacob's in-class struggles:

One day in scool it started as and ordinary day but at resec we hade a safty meet and I got my posit (post) I got to raes the flag It was cool because every morning I hade to come to scool erly to raseis the flag and tack down the flag I was cool because I was incharg of the flag that is one thing that happond to me

While both of these children are quite different in style and personality, both manifest the signs of a shut-down learner.

The signs of a shut-down learner typically start to emerge in the upper elementary grades, and become much more pronounced by high school.

They include:

- A sense that the child is increasingly disconnected, discouraged, and unmotivated
- Fundamental skill weaknesses with reading, writing, and spelling, leading to diminished self-esteem
- Increased avoidance of school tasks such as homework
- Dislike of reading
- Hatred of writing
- Little or no gratification from school
- Increasing anger toward school

Understanding the formula of shut-down learners

Shut-down learners are children who become academically discouraged and disconnected from school over time. A simple formula helps to explain how kids become shut-down learners:

Cracks in the foundation + Time + Lack of Understanding + Strained Family Communication = Shut-Down Learner

Understanding this formula will help parents of children like Emma and Jacob to be in a better position to take appropriate action.

Cracks in the Foundation: Cracks in a child's learning can usually be

identified as early as preschool and kindergarten age. Indicators during this period are easily identified. Does your child have trouble learning letter names and their sounds, for example? By first grade, is your child taking steps toward blending sounds? In middle to upper elementary school, is writing a laborious, often agonizing process for your son or daughter?



If the answer is “yes” to these questions, it does not necessarily follow that your child will become a shut-down learner. However, like cracks in your house that expand if unaddressed, it is important to act to prevent academic cracks from widening. Otherwise, they will contribute to discouragement over time and a child ultimately shutting down.

Lack of Understanding: In my evaluation of shut-down learners, I have found that many receive work on a daily basis that they simply cannot handle, causing them unnecessary frustration. Too often, parents and teachers do not understand the skill deficits that are causing a child difficulty. For example, I recently tested a fourth-grader who struggled

to read certain words presented in a text, including “porcupine,” “passage” and “amazement”. Since most fourth-graders read silently to themselves, her teacher and parents mistakenly believed that the student had a comprehension problem, when she was actually experiencing difficulties with word-reading and decoding.

Additionally, many children who struggle in school simply do not have problems deemed to be “severe enough” to warrant special education. For those children, parents will need to seek outside remedial help in the form of tutoring, where available.

Strained Family Communication: The beginning of homework time often marks an increase in the household temperature, as screaming and arguing become part of the landscape. Strained communication

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around homework can be overwhelming for families and can contribute to a child's becoming a shut-down learner.

Addressing (or preventing) shut-down learners

1 Trust your gut: If you believe your child is experiencing difficulties at school, listen to yourself. Don't wait, or fall for such oft-used statements as, "You know how boys are," or "She'll grow out of it." Act on your feelings even if your child has been deemed ineligible for school services. Consult a trustworthy, competent person outside of school whom you feel comfortable with, to assess your child.

2 Know what you are targeting: If your child's assessment has identified issues of concern, chances are an area in your child's reading needs addressing. There are essentially two types of reading problems: in the first, the child has trouble decoding words and reading fluently. In the second, the child can read fluently, but experiences great difficulty understanding what he or she has read. Get clear on the exact issues that you hope to resolve. Don't scattershot remediation.

3 Take the heat out of the interaction: Try to step back a little bit and turn down the heat

within the house. The daily ritual of yelling, pecking or nagging never leads to positive change. When was the last time your child said, "Thanks for yelling, Mom, I see your

point. I'll get down to business"? Right. Never. Why persist? Your kids are probably feeling overwhelmed by homework that they can barely handle. In raising the heat, you're simply adding stress to their lives. Turn down the temperature. Kids need emotional fuel to tackle their school difficulties, especially those kids who derive little gratification from their efforts. Look for the small things that your child is doing well. Statements, like, "Wow, I like the way you took out your work tonight without my asking," can really mean a lot to a child, especially one who might be a bit discouraged.

4 Find someone to connect with and mentor your child in school: The shut-down learners I know do not feel very good about themselves and they do not see their true strengths. If your child is of

middle-school age or older (those preteen and teenage years when the development of a sense of self is critical), it is particularly important for him or her to have at least one

Do something fun and enjoyable with your child. Try not to let school problems set the tone for the entire household and all of your interactions.

person in school who really values him or her and will rally on your child's behalf – even if he or she isn't succeeding academically.

5 Maintain a sense of equilibrium: Do something fun and enjoyable with your child. Play a board game or do an arts and crafts project together. Most kids would enjoy doing an activity like that with you. Try not to let school problems set the tone for the entire household and all of your interactions.

6 Support your child: Academic discouragement is debilitating to children and families. Connecting with your child's natural strengths and letting him or her know that you are both on the same "team" can make an enormous difference in preventing your child from becoming a shut-down learner. ■



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Dr. Richard Selznick is a child psychologist and the director of the Cooper Learning Center, Department of Pediatrics, Cooper University Hospital in New Jersey. He is the author of *The Shut-Down Learner: Helping Your Academically Discouraged Child* (www.shutdownlearner.com).

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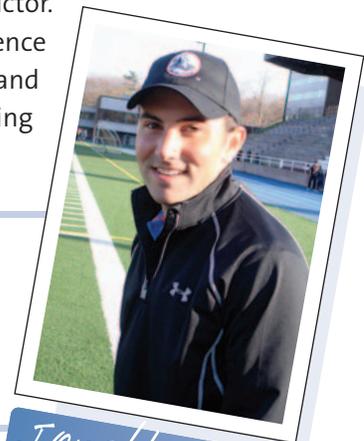
A tribute to individuals and organizations that are making a mark in the exceptional community

by LINDSAY LAFRENIERE

Jonathan Howard recently devoted a year of his life to raise awareness about Autism Spectrum Disorders (ASD) and support children and their parents affected by the condition. Rather than simply writing a big cheque, however, Jonathan donned his best running shoes for the run of his life – across Canada. Over 199 days, the 26-year-old Mississauga native ran from St. John's to Victoria, covering an average of 40 km – the length of a single marathon – daily.

While Jonathan does not have any relatives with autism, as a teen he had worked with children with ASD as a camp counsellor and swim instructor. After graduating from McMaster University with a B.A. in Political Science and Labour Studies, Jonathan wanted to give back to the community and decided to make a difference for the one in 166 Canadian children living with autism.

**“It’s your decisions,
and not your conditions,
that determine your destiny.”**



Jonathan Howard

It was in the spring of 2008 that Jonathan launched the first ever cross-country run to raise autism awareness and funds for the Autism Society of Canada. He named the event Run the Dream – a beckon to all children, regardless of abilities, “to dream as though they’ve never failed.” The run raised \$60,000 for provincial and territorial Autism Society affiliates, to provide respite and other services for those touched by autism.

Today, Jonathan is pursuing a career in commercial real estate while continuing to garner support for Run the Dream. He now advocates for a national healthcare strategy to assist those affected by ASD and to further research of the disorder. He is currently working on a book based on his Run the Dream experience. Slated for release in December, Jonathan hopes it will inspire young adults to visualize, plan and follow through with dreams of their own.

For more information on Run the Dream, visit www.runthedream.ca

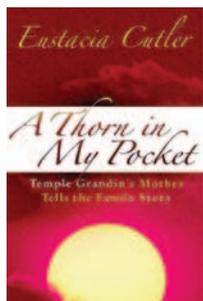
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& Classics

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

A Thorn in My Pocket: Temple Grandin's Mother Tells the Family Story

By Eustacia Cutler
Future Horizons Inc., 2004
228 pages, \$26.50



Once in a while, a book comes along that's so powerful, so moving, it becomes an instant classic. Such is Eustacia Cutler's

2004 tell-all autobiography *A Thorn in My Pocket*, which offers both hope and inspiration for parents who may not be able to see beyond their current struggles surrounding their exceptional children.

With humility, passion and brutal honesty, the mother of renowned

scientist and university professor, Dr. Temple Grandin, recounts her life and innumerable challenges as the mother of a child with autism during the 1950's – the "Leave-it-to-Beaver" period, as Cutler calls it, when autism was both an unknown and hopeless condition and Bettelheim's "refrigerator mother" theory reigned supreme.

In the face of doctors and educators who banded against her, an abusive husband consumed with institutionalizing Temple and painting his wife as insane, and the ultimate dissolution of her marriage, Cutler's resilience and fortitude prevailed and she emerged as Temple's foremost advocate. Yet more than simply striving to survive and cope day-to-day, the indomitable Cutler resolved to create an identity for herself beyond her role of single mother to four children. And so began Cutler's new life; one marked by fulfillment, the pursuit of dreams, and numerous accomplishments – including graduating from Harvard, remarrying, performing in

"She's retarded! You know it but won't admit it!"

"She's not retarded."

"Yes, she is. You just can't face it."

"OK, for the sake of argument, let's say you're right. We'll call her 'retarded,' and I'll say I'm facing it."

Now what? You want to put her in the Salvation Army box behind the A&P?"

- *A Thorn in My Pocket*

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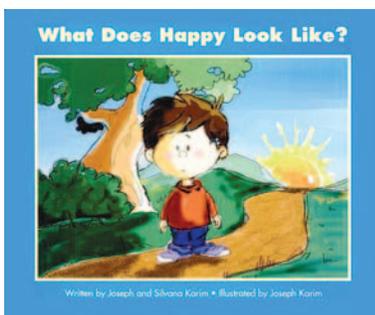
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various theatrical productions and ultimately joining Temple on the autism lecture circuit.

Beyond a glimpse into Temple's largely privileged upbringing as the child of Ivy League-educated parents, whose summers were spent ocean-side at the family cottage, readers will gain a critical understanding of autism and its various manifestations. Perhaps most valuable, however, is the book's global applicability to anyone touched by disability, regardless of the condition; for Cutler's experiences represent a microcosm of the dynamics that typically play out in lives of those connected with exceptional relatives. ■

What Does Happy Look Like?

by Joseph and
Silvana Karim
Autism Asperger Publishing
Company, 2009
46 pages, US \$18.95



by LAUREN SILVER

Written by husband and wife duo Joseph and Silvana Karim – parents of a child with autism – *What Does Happy Look Like?* is a useful resource to help kids who are predominantly visual, concrete thinkers to identify the feelings and emotions of others, as well as their own. In concise, straightforward language and easy-to-read sentences, five emotional

*What does sad look like?
Sad is a rainy day that stops me
from going outside to play.
Sad is being sent to timeout for
pushing my little brother.
Sad is dark blue and cold.*

- *What Does Happy Look Like?*

states – happiness, sadness, fear, anger, and love – are assigned individual colours and defined by two experiences associated with them. “Happy” is bright yellow, for example, and happy is “flying on an airplane and sitting by the window.”

Children ages 5 to 8 will be drawn to the vivid and colourful illustrations that accompany each page of text. The sizes of the caricatures in the drawings are substantial, which will facilitate readers' ability to identify characters' emotions based on their clear facial expressions.

A series of activities following the story enables children to practice

their emotion-recognition skills. One activity asks readers to draw eyebrows and mouths onto blank faces in order to convey given emotions, while another encourages kids to think of five situations in which one would experience the emotions mentioned in the book.

Although not a novel concept and somewhat reminiscent of Dr. Seuss' 1998 *My Many Colored Days*, *What Does Happy Look Like?* is an excellent tool for children to learn about the visual cues associated with certain emotions and put them into practice. ■



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Make It Count

Teaching your kids money smarts at an early age will help them down the road

by LISA TABACHNICK HOTTA

Saving money: it's an easy enough concept to understand. However, an examination of today's economy and Canadians' burgeoning debt indicates that sound money management still eludes many. There is good news though – tools and resources are available to help parents and their children to become financially savvy.

Ainsley Cunningham is the manager of education and communications for the Manitoba Securities Commission. Cunningham and her team, along with other provincial securities regulators and the Canadian Securities Administrators (CSA) have designed *Make It Count* – a financial literacy program and guide for parents, educators and kids. **MakeItCountOnline.ca** is the companion website which offers tips for parents, money-focused activities for younger children, and simple lessons on budgeting, debit-card use, common sense spending, donating and investing – all at no cost to users.

Start Early

“We recognize that teaching kids who are five and six years old about money can be very difficult,” says Cunningham, who urges parents to appreciate that early education



will help their children as adults in the long-run. “Parents don't wait until their children are 14 or 15 to teach them about manners,” she says. “The [same philosophy can be applied] to teaching children about finances.”

Simple but meaningful challenges on the *Make It Count* website will help kids make a connection between wants, needs and long-term savings. An online budgeting tool helps youth save for everything from cell phones to movie parties at home, while allocating other funds to favourite charities or even university.

There are also many suggestions for parents and educators searching

for techniques to teach kids about financial planning. For instance, you can turn a simple trip to the grocery store into a lesson in money management. At the supermarket, ask: “What's the cost difference between a take-out lunch and a homemade packed lunch?” Or, go a step further and challenge your child or students to assemble a \$3.00/per person wholesome lunch menu in the span of 45 minutes. Participants will enjoy the opportunity to be creative, discover new foods and learn about the power of a dollar all in one shot.

Get fit (financially literate)!

What is financial literacy and why is it so important? Simply put, it's the ability to understand finance. And, while many high schools have introduced courses on finance further to the federal government's 2009 Financial Literacy Task Force initiative, some parents and educators would like to see these lessons begin earlier. While a recent survey conducted by the CSA revealed that 78 percent of Canadians believe that teaching financial skills is among the most important things a parent can do for their child, less than half of parents with children 18 or younger have actually taught their children about personal finances and investing.

Parents questioning the importance of teaching kids about money management at an early age may wish to consider the recent quandary of 30-year-old Adam Goodman of Toronto. Goodman, author of *Following the Goods: Financial Management for the Young and Ambitious*, offers himself as an example of what happens when one is not properly educated on money management as a child.

You can turn a simple trip to the grocery store into a lesson in money management.

While he now has an MBA under his belt and a career in the telecom industry, Goodman “spent the first 26 years of my life spending every dollar I made.” The result: he ended up broke and living in his mother’s basement in his late 20s. Awed by a friend’s successful savings endeavour, he changed his financial ways. “I realized I’m not the exception – I’m the norm,” warns Goodman, who wrote his book (and blog) as a way to share his story with young people and get them thinking about money. “The real issue is that, throughout my youth, there was never any context around the financial literacy education I received, whether from family, friends, teachers, or professionals. Everyone said ‘save your money’, but no one said what to save it for.”

PHOTO: http://bcg.ca/media_centre/csa/

Getty Stewart of Winnipeg and her children Aidan, 8, and Melanie, 6, do an activity from the Make It Count guide.



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In

Focus

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

Put it in Writing

PHOTO: JULIAN HABER



“How can I know what I think till I see what I say?”

When I first read this quote by novelist E. M. Forster, I immediately understood its relevance with regard to the value of writing as a therapeutic medium. It also has implications in terms of writing’s value as a tool for problem-solving, advocacy, and communicating with professionals – actions regularly performed by parents of exceptional children.

At one time or another, most of us have had the experience of leaving a meeting feeling frustrated around our inability to communicate a point, or having forgotten to ask important questions. Whether at medical appointments, parent-teacher meetings, intake interviews for schools and programs, therapy consultations, or the often-dreaded case conferences where parents feel the onerous responsibility to be their child’s voice in a room full of professionals, the ability to communicate clearly and effectively is critical.

That’s why I often recommend to my clients that they take the time to prepare for meetings by summarizing their concerns, questions and children’s histories on paper. Doing so will not only help to avert that “slap on the forehead” later; it will also enable you to organize your thoughts and ensure that you will present them cohesively. Moreover, it will help to reduce the risk that your emotions or frazzled nerves will get in the way of effective communication.

Whether you choose to distribute a printed version of your notes to those in attendance, read all or parts of it aloud, or just keep it as a reference to consult during a meeting, the following are some important tips to keep in mind when consolidating your thoughts in writing:

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Consider the audience. What are the goals of those with whom you are meeting? What questions might they ask you? What are the most important things you think they need to know?

Consider your own needs. What do you hope to achieve from this meeting, both short- and long-term? What questions do you need answered? What do you need others at the meeting to understand about your child?

Find a common ground. It's often helpful to start from a place where everyone shares a common goal. It might be as narrow as wanting to ensure that an upcoming medical procedure will be as comfortable as possible for your child, or as broad as wanting your child to reach his or her fullest academic potential. But it's always a good idea to briefly express this common goal at the beginning, to keep everyone's eyes focused on the same prize.

Don't worry about writing skills. No one's expecting you to be a professional writer. The purpose is to communicate, not to achieve perfect spelling and grammar. Don't worry about using professional jargon. Just express yourself in your own words.

Take plenty of time. Give yourself time and space to go back and review what you've written with fresh eyes. Then edit any parts that require clarification, trimming, or elaboration. It's often helpful to have someone else, like a trusted friend or family member, read it and provide feedback. During the course of writing the first draft or reading it back, you might glean some new insights. Make sure you have time to reflect and to edit the material until you're satisfied with it.



A mother's efforts are duly noted

A client of mine was determined to have her daughter seen by a highly respected doctor in a very specialized area. She was told to fax her referral so the specialist could decide if she should be "granted" an appointment (which would, due to a long waiting-list, only take place in months' time). The mother was alarmed. There was so little information about her daughter's condition in the referral, and so much at stake around her daughter's future that depended on this particular doctor's assessment.

Prior to faxing the referral, I advised the mother to compose a summary of her daughter's long medical history. She spent days penning and reviewing it, making sure the summary did not reflect the emotional outpouring of a distraught mother, but rather a factual, rational justification of the need for this appointment. She faxed it off and held her breath. Within 48 hours she was sitting in the doctor's office with her daughter.

The Abe Gold Learning and Research Centre and the Quebec Chapter of the American Association on Intellectual and Developmental Disabilities present:



Gary Mesibov Ph.D.

&

Jed Baker Ph.D.

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Ask yourself some tough questions. As you review your notes, ask yourself if you've let your emotions get in the way of your objectivity. The meeting is not the forum to vent your frustrations (although this can be a very healthy exercise, called therapeutic writing – a topic we'll explore in the second half of this two-part series). The purpose in penning these notes is to convey accurate, thoughtful information that will *help* your child in some way – not alienate others. If you've offered valid and constructive criticism, have you also suggested possible alternatives? You know what works and what doesn't with your child, but others may not. Can you use your insights to help achieve your mutual goals?

Writing to communicate, problem-solve, or advocate is not only useful in preparation for important meetings



You know what works and what doesn't with your child, but others may not. Can you use your insights to help achieve your mutual goals?

like case conferences and medical appointments. It can also be employed to maintain consistent communication between parents and teachers via “communication books” or agendas, etc. In some cases, a few lines between you will suffice.

You might also wish to keep a written record of your child's personal, medical, and/or educational life, including specifics like relevant dates, numbers, and even anecdotes. It's easy to forget details, which can often be extremely helpful years later. Additionally, you may be inclined to develop the habit of composing brief e-mails to all those in attendance at a given meeting to confirm your mutual understanding of the outcomes and to ensure that nothing has been misinterpreted.

However you choose to employ writing as a tool, remember that conversations can be forgotten or misunderstood, but written words will provide you with accuracy and accountability, and guarantee that your voice will truly be “heard.” ■

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

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Eye Problems Affecting the Premature Child

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

by JOHANE M. ROBITAILLE MD,
FRCS(C), Department of Ophthalmology
and Visual Sciences, IWK Health
Centre, Dalhousie University

The first efforts to assist premature babies were recorded in the late 1800's. The creation of neonatal intensive care units providing incubators and oxygen was popularized in the late 1930's and significantly improved the survival of tiny infants who were born prematurely. Eye problems that were rarely noted prior to this practice soon became evident, and thus began the first epidemic of retinopathy of prematurity, also known as ROP, a condition that we will explore in great detail in the paragraphs that follow. In spite

of advancements to help prevent blindness from ROP, prematurity remains one of the leading causes of severe visual impairment in high income countries and is particularly prevalent in developing countries.

Two specific aspects of vision are particularly vulnerable to damage in infants who are born prematurely: the retina and the visual pathways connecting the eye to the part of the brain responsible for vision. According to Canadian guidelines, all infants who are born at 30 weeks gestation or earlier (full-term being 40 weeks) and who weigh 1500 grams (3.3 pounds) or less at birth are at risk of vision loss. U.S. guidelines suggest 32 weeks gestation as the cut-off. The risk is greatest in those who are born earliest and smallest.

The retina is the inner lining of the eye responsible for capturing images, similar to the film used in old-style cameras. As the retina matures over the entire pregnancy period, blood vessels start to grow

at about 12 weeks. They start in the back of the eye, and spread by branching out and extending along the retina until they reach the retina's front edges. Vessel growth is only complete when the baby reaches term. In premature, at-risk infants, the fine coordination of retina and blood vessel maturation can be compromised, leading to ROP.

ROP is a condition that happens when the retina blood vessels have not grown all the way out to the retina edges. The earlier a baby is born, the less the vessels have had a chance to develop and, therefore, the area of the retina that has no blood vessels will be greater. Most ROP is mild and will heal without complications that affect vision. There are various degrees of ROP severity, however, described as stages, which occur at the intersection where the retina that has vessel supply meets the part that does not. The worse stages lead to scarring, retinal detachment and vision loss at the detachment site.

Fortunately, this complication is rare thanks to laser treatment that significantly reduces its occurrence. Such treatment is offered to all infants whose ROP is deemed severe enough to place them at risk of retinal detachment and vision loss. Laser treatment reduces the

screening starts at roughly four to six weeks of life and continues every one to three weeks until the ROP has regressed or the blood vessels have fully developed. If, during the screening process, ROP becomes sufficiently severe, the eye doctor will recommend treatment.

Despite an extensive list of known risk factors, it is impossible to predict which babies will develop severe ROP. For this reason, all at-risk infants are screened by an eye doctor who specializes in the condition.

chances of complications by roughly 85 percent. In general, severe ROP requiring treatment occurs in about 8 percent of at-risk infants. If severe ROP does progress to retinal detachment in spite of treatment, surgical repair is very difficult to perform and success is limited.

In general, preemies who have a stormier course following birth are at higher risk of ROP. Despite an extensive list of known risk factors, it is impossible to predict which babies will develop severe ROP. For this reason, all at-risk infants are screened by an eye doctor who specializes in the condition. This

Otherwise, it will simply be left to run its course, as mild ROP does not affect vision long-term.

The second part of the visual system that is susceptible to damage from premature birth is the part of the brain which houses the visual pathways that connect directly to the eyes. The damage is called cerebral visual impairment or cortical visual impairment, and is particularly common in infants who have neurological complications related to prematurity, such as cerebral palsy and hydrocephalus. A visual function assessment is critical to help these children and their families

cope as best as possible with this disability that can lead to blindness in its most severe form. This requires the cooperation of a number of specialists, including a pediatric ophthalmologist, a visual function specialist (i.e., a low vision specialist), neurologist, and pediatrician, among others, depending on a child's specific needs and local resources.

Long-term follow-up is critical for all prematurely born children with the potential for vision problems. For those who develop severe ROP, reduced vision, nearsightedness and astigmatism are common. In addition, there remains a small but significant risk of retinal detachment that warrants annual check-ups with an eye doctor. Infants with even mild cases of neurological complications of prematurity (e.g. cerebral palsy and hydrocephalus), are at risk of amblyopia,¹ strabismus,² and vision loss from damaged visual pathways that also warrant regular assessments, especially while the visual system develops until about 10 to 11 years of age. Customized follow-up at any time may also be recommended based on specific situations. ■

1 See Exceptional Family, Vol. 4 No. 3, Spring 2009

2 See Exceptional Family, Vol. 4, No. 4, Summer 2009

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Following completion of an ophthalmology residency at Laval University in Québec City, **Dr. Johane Robitaille** (MD, FRCSC) continued training in pediatric ophthalmology and strabismus surgery, followed by neuro-ophthalmology at University of Iowa, and ophthalmic genetics at Johns Hopkins University. She is currently an Associate Professor in the Departments of Ophthalmology and Visual Sciences, Pathology and Pediatrics, at Dalhousie University in Halifax.

Parentspeak

A forum that gives voice to parents and grandparents of exceptional children



Karen Congram and her children Abby, 10, Ben, 13, and Caroline, 7, at the Lake Huron beach in Goderich, ON.

A Day without Screaming

by KAREN CONGRAM

When I first heard the word “respite” with reference to our daughter Abby, I was insulted. The nerve to suggest that I needed help caring for my child! Still in the adrenaline-driven Supermom stage, I had no idea of the emotional and physical toll this journey would take. Looking back, I needed to learn the hard way about the value of pacing myself. No one could have explained that to me at the time. You have to live through it to understand it.

Our second of three children was born ten years ago. Abby was declared a “perfect” baby and developed in a typical way for the first year of her life. Our journey as an exceptional family began shortly after that, when Abby was not bearing enough weight to crawl or walk. A simple suggestion by her doctor that we run some tests to rule out problems was enough to send me on the first deep dive of emotions. There was no way to control the wave of anxiety that would wash over me again and again throughout the next few years.

There would be four years of testing and searching before we obtained a confirmed diagnosis of Rett syndrome, a neurological condition characterized by a period of normal development followed by the loss of functional mobility. Repetitive hand movements replace purposeful fine-motor development, for example. The disorder affects girls almost exclusively, and is most commonly misdiagnosed as autism or cerebral palsy.

Abby persevered through physical therapy and began to walk on her

own at the age of 26 months. Although she began to develop speech, she lost all words after her second birthday. She was once able to manipulate toys and turn the pages of a book, but she lost almost all functional use of her hands.

I went through a complex grieving process in those years, and likely will continue to mourn the loss of my child's typical development. After the initial shock of realizing that something was wrong with my child, I went into fix-it mode. I was willing to take Abby to any number of specialists and appointments and to put her through any number of tests to get to the bottom of the problem and to find a way to solve it. For the most part, I was sent further along the road of false hopes and disappointments as the clock kept ticking, with no answers.

Meanwhile, following experts' advice, I took Abby to every type of therapy for early intervention on the premise that if she could just get more therapy, she would develop and "catch up." It still makes me cringe to remember Abby going through the most difficult stage of regression while I insisted that she just do more therapy. Hindsight tells me there was nothing I could do to stop the loss of skills or her sensory processing disorder but I just kept pushing harder in a vain attempt to fix the problem.

The physical exhaustion from all the appointments, medical tests, and therapy, the constant anxiety of not having a diagnosis, and the creeping realization that this was not a problem that could be fixed by anyone were enough to put me over the edge. But none of it compared to what it was like to live with the screaming.

A simple wish

My husband and I would sometimes contemplate our greatest wish for Abby's future: Would it be that she would walk? Talk? Use the toilet? Dress herself? Complete medical school? In no time, however, my



greatest wish for Abby – and for all of us – was quite simply, to have a day without screaming.

For a few years, Abby's screaming was constant. She had a scream for every emotion or need, but also just for no apparent reason. She screamed day and night. I would find her in her room alone in the middle of the night, screaming. People have tried to describe the screaming in words. One stranger

in a grocery store line said he thought it was an exotic bird. To use the word "piercing" would be a tremendous understatement. Abby's screaming was so loud and shocking that it sent everyone within earshot into the fight-or-flight response.

I found it frustrating to see this particular symptom listed as "agitation" in the diagnostic criteria. "Agitation" was a euphemism for Abby's behaviour at that stage; you wouldn't look at her and say, "Oh, she's agitated." You would say, "What's WRONG with this child?!" In our search for a diagnosis, we would always list screaming as the top symptom, only to have it brushed aside as irrelevant. Often we were told that we had a typical preschooler who threw tantrums and that we were overreacting. We even followed a referral to a behavioural psychologist so that we could start a behaviour modification program for Abby. It was a very interesting experience, but the screaming didn't stop.

And so we began to alter our behaviour as a family – staying home more, taking turns looking after Abby while the others attempted to participate in the regular activities of life, making use of a network of relatives and friends to help us out. I felt guilty for leaving Abby out of so many activities, but I felt guilty

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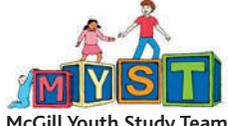
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McGill Youth Study Team

for everyone else, mostly her siblings, when we brought her along. Her unhappiness and screaming would be the entire focus. Leaving her at home seemed to be the best compromise.

During the turmoil of our family's "lost years", a support worker from a local agency found a way to get around my pride. She explained to me that by making use of provincial programs and respite funding, I could increase Abby's educational and therapeutic support. It would be good for Abby. And it was. It was good for the whole family, I soon realized. It was our chance to have that day without screaming. It was a way of integrating Abby back into many community activities and a way of establishing some normalcy for her siblings. Gradually, we learned to utilize and accept available funding and saw how the relief made a positive difference for all of us. I learned to put my pride aside for



Sisters Caroline and Abby.

the good of our family and for myself. I learned to recharge my batteries before running out of the energy needed to support all of my children.

Today, Abby needs assistance with every aspect of daily living. She is

fortunate to have retained the ability to walk, but she battles apraxia¹ daily in an effort to control her movements. She cannot walk a straight line and she tires easily, due to low muscle tone. But Abby has reached a new stage of Rett syndrome.² She is much more mel- low and content than she once was. Her beautiful smile and sunny disposition are what you notice first, despite her multiple disabilities.

Abby will sometimes go for days without screaming or crying. But she also has moments of unexplained sorrow and discontent. Nothing compares to the helpless

feeling of trying to comfort an inconsolable child. Sometimes, I will simply hold her and we will both cry together.

The strength it takes to live like this does not come to anyone naturally. As a family, we require immense support. We now welcome service providers into our home and pack Abby's suitcase for her occasional weekend at the local Rotary Respite House. Expanding our family support system has become a necessary and welcome part of our life. The notion of going it alone seems ridiculous to me now. But I had to learn that the hard way.

The people who devote their time, energy and enthusiasm to respite care are providing a priceless gift to countless families. It's impossible to measure the success of their work. It's easy to take a healthy, happy family for granted. ■

1 The inability to plan and execute motor functions, despite having the desire and the physical ability to perform them.
 2 There are four distinct stages of RS and Abby has supposedly reached the third stage, which is easier than the second. The stages of RS, however, vary from child to child.

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Insights

A compilation of upcoming conferences and training sessions of interest

MARCH

15-17 Mental Health, Sensory Processing and Challenging Behaviour

Fraser Valley Child Development Centre

This dynamic workshop provides a current scientific review of the neurobiology of sensory processing disorders, deepening participants' understanding of brain-behaviour relationships in the pediatric population. Suitable for clinicians, psychologists, therapists, social workers, special educators. \$450. 9 am - 4 pm. 102 - 32885 Ventura Ave, Abbotsford, BC. Info: Kirstie Glasgow (604) 852-2686, kglasgow@fvcdc.org or nextstep@fvcdc.org.

of adolescents and adults with FASD, their families, service providers, and communities. \$595. 8 am - 5 pm. 655 Burrard Street, Vancouver, BC. Info: (604) 822-7524, ipad@interchange.ubc.ca or www.interprofessional.ubc.ca

sive planning and how to embed them into the child's day, particularly in inclusive settings.

Professionals: \$50, Parents/Students: \$35. 8 am - 4 pm. 13800 boul. Pierrefonds, Pierrefonds, QC. Info: (514) 345-8330 x319, info@goldlearningcentre.com or www.goldlearningcentre.com

MAY

21 Brenda Smith Myles, PhD: "Promoting Positive Social Skill Development"

The Abe Gold Learning and Research Centre and LBPSB

Explore social skills supports for students with high functioning autism and Asperger's. Social skills activities will be discussed in the context of comprehen-

EF welcomes your Insights!

To publicize an upcoming conference or training session FREE of charge, contact us at feedback@exceptionalfamily.ca.

Publication will be subject to the discretion of the editor and publisher.

APRIL

12-13 2010 Lecture Series: Dr. Gary Mesibov and Dr. Jed Baker

The Abe Gold Learning and Research Centre

Dr. Mesibov will highlight the major characteristics of more functional individuals with ASD and their differences from typical peers. Current educational approaches and issues related to personal development and quality of life will also be explored. Dr. Baker will discuss how to handle meltdowns and design behaviour plans to reduce frustration and anxiety. Students: \$25, General: \$75, Professionals: \$170, all prices per day. 8:30 am - 4:30 pm. 3500 boul. Du Souvenir, Laval, QC. Info: (514) 345-8330 x319, info@goldlearningcentre.com or www.goldlearningcentre.com

14-17 Fourth National Biennial Conference on Adolescents and Adults with Fetal Alcohol Spectrum Disorder

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CLARIFICATION

The Winter 2009 issue of Exceptional Family incorrectly identified adoptive parents Yvonne and Malcolm Hutton in a photo.

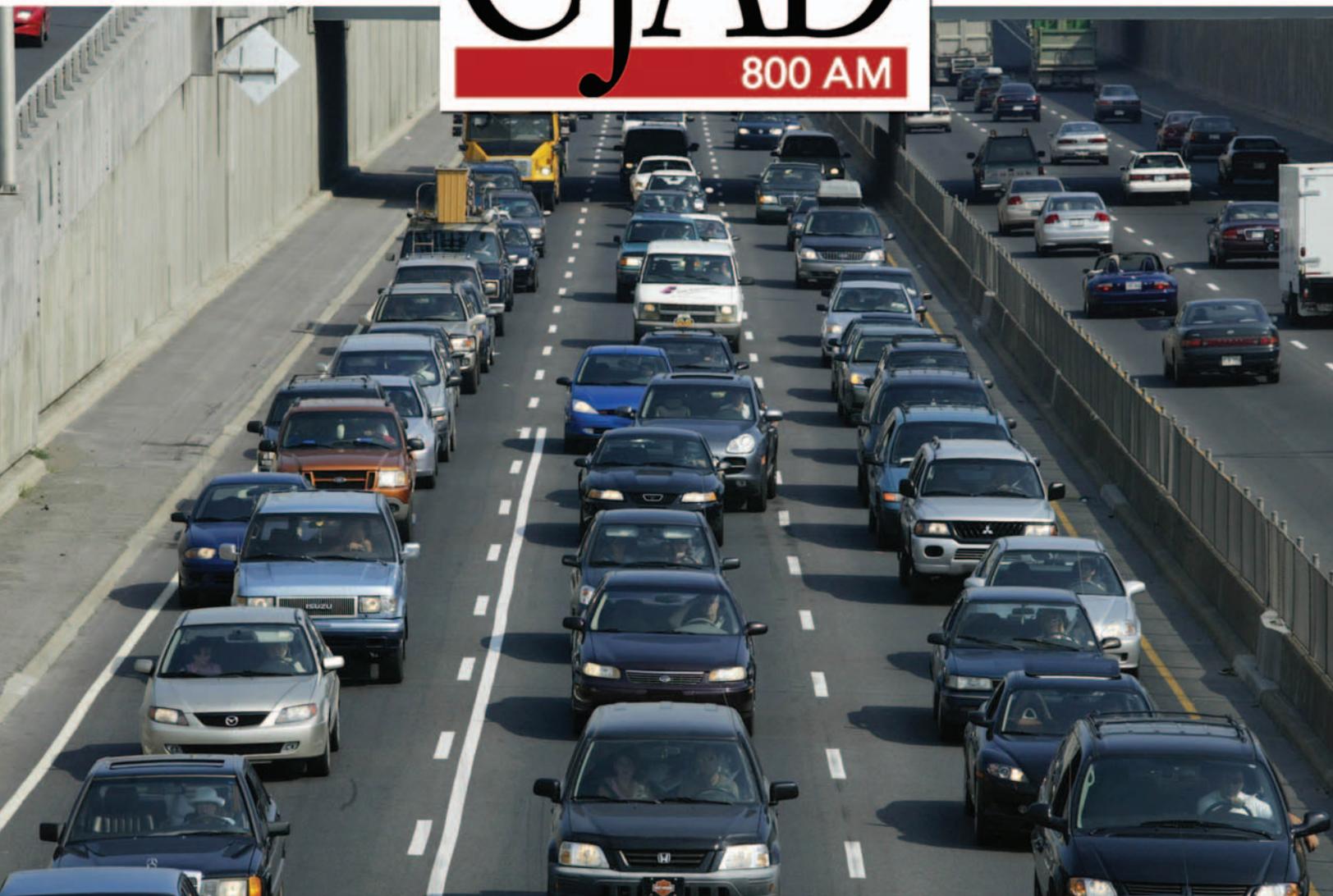
Above is a picture of the couple. EF regrets the error.

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