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OF EXCEPTIONAL CHILDREN

Vol. 5 No. 1 • Fall 2009



Family

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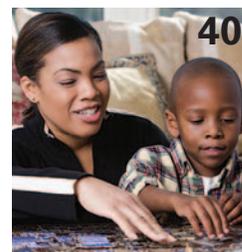
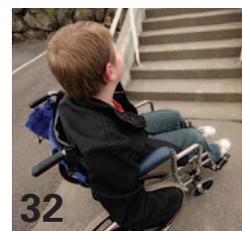
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PUBLISHER'S NOTE



PHOTO: JULIAN HABER

A Reason to Celebrate

As we toast our fifth year of publication, I'm delighted to announce that *Exceptional Family* has won first place in the 2009 External Publications Category of the Health Care Public Relations Association's annual Hygeia Awards. The Hygeia Awards recognize excellence and honour outstanding accomplishments in healthcare communications across Canada. This is the second consecutive year that our publication has won a Hygeia Award.

As we savour the successes of the past four years, we also raise our glasses to you – our readers, editorial board members, subscribers and advertisers, for your ongoing loyalty and enthusiasm. We are proud to have graduated from a fledgling magazine whose future was initially uncertain, to one that is officially here to stay. Our quest to provide you with fresh insights and innovative tools for your exceptional family has only just begun. Here's to the next five years!

Cheers,



Warren Greenstone

Executive Director, Miriam Foundation
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FROM THE EDITOR



PHOTO: JULIAN HABER

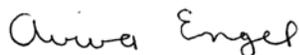
Sweet Success

The endowment of our most recent award by the Health Care Public Relations Association is icing on the cake marking our fifth anniversary. While this national acclaim brings us tremendous joy and pride, equally as meaningful is the feedback we have received over the years from readers and professionals in medical and mental health fields in praise of our one-of-a-kind resource. As is our annual custom, we have reprinted a selection of your comments from the past year (page 23).

Last winter, we introduced *Parentspeak*, an exciting new forum that gives voice to parents and grandparents of exceptional children who wish to share personal stories of triumph, joy, heartache or struggle. The response to this latest feature has been overwhelming, and has highlighted the degree to which exceptional caregivers long to connect with one another. To that end, we're delighted to include a bonus feature in this issue called "Sharing Our Stories, Seeking Support" featuring candid reflections on special needs parenting (page 36).

Not ones to rest on our laurels, we have also redesigned and expanded the scope of our ever-popular *Inspiration* feature; *Imprints* pays tribute to individuals and organizations that are making a mark in the exceptional community (page 31). We invite you to check it out, and nominate those who you feel deserve public recognition at imprints@exceptionalfamily.ca.

As families shift gears from the relaxation of summer to the productivity of the fall, may the coming year bring you opportunities to celebrate sweet successes of your own.



Aviva Engel

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PHOTO: RON BOUDREAU

Justin Hines: Singer-songwriter with Soul

Chart-topping musical sensation strikes a chord with fans of all abilities, and proves that anything is possible

by ALESSANDRO NICOLO

Justin Hines was born to be a musician. Even before the 27-year-old award-winning singer-songwriter from Toronto could utter a single word, his musical abilities were strikingly apparent to those around him. Although born with Larsen syndrome, a rare condition that limits his mobility, Justin has risen above his physical challenges by tuning in to his emotions and embarking on a lifelong soul-searching journey through music. He has discovered he's not alone on the ride, helping to inspire thousands of people from all walks of life along the way. Blessed with a powerful combination of talent and determination, Justin has been striking a chord with Canadian fans since he signed on with The Orange Lounge Recording Company in 2007.

"Justin's appeal is broad. His popularity spans right across the country," says Justin's manager Aubrey Winfield, president of Orange Lounge Recordings and JAD Media. Having been part of the music scene for 30 years, Winfield can testify to the extent of

the function and venue, Justin's audiences consist of anywhere from 200 to 50 000 people. Justin acknowledges that his wheelchair certainly adds a unique dimension to his performances; it's an attention grabber even before he sings a

"My aim is to have people see me for who I am... If they're still talking about my physical disability after I sing, then I didn't do my job."

Justin's worth as an artist. "Justin's music is categorized as Pop/Adult Contemporary but he literally attracts people of all ages and backgrounds."

And Justin's schedule is jam-packed, with approximately 10 shows including charity and corporate events scheduled monthly. Depending on

single note. But he takes it all in stride and doesn't stress over others' initial impressions of him. "Getting attention is not hard because it's built in me," says Justin. "But my aim is to have people forget the wheelchair and see me for who I am. I can't control what people think when they first lay eyes on me. If

they're still talking about my physical disability after I sing, then I didn't do my job."

Triumph over adversity

With only a few thousand documented cases in the world, Larsen syndrome is a congenital condition in which multiple joints, including the hips, elbows and knees, dislocate and then permanently fuse together once they lock back into place. It begins in the womb and is marked by distinctive features in the face, hands and bones. Common characteristics include widely-spaced eyes, a prominent forehead and short hand bones. "A good way to describe it is the joints find a new pocket to sit in and live. It's pretty cool when you think of it. The human body is a fascinating and intricate piece of machinery," Justin reasons, in his typically upbeat fashion.

While diagnosis of the condition has come a long way since he was a youngster, identifying Larsen syndrome isn't a straightforward process. "It's a hard condition to pinpoint when you're a child, because your joints are still forming. As a result, I was misdiagnosed a couple of times. At one point, doctors thought I had cerebral palsy."

Born with severe sclerosis,¹ Justin estimates that he's had about eight

corrective surgeries in his lifetime; he can't recall the number exactly, because he was only five when the last one took place. What he knows for certain is that he underwent the most critical operation at age two. In order to minimize continued pressure on his spine – the strain of which was life-threatening – doctors inserted a piece of bone from his hip in the spinal root to stabilize his neck. "[The incision] was way up in my neck – the C3 section of the spinal cord to be exact. It was a risky surgery. But it saved my life," says Justin.

"It must have been interesting to have to live with a brother like me, always getting attention for my disability, and then being in the spotlight for my career."

Although he still encounters daily physical challenges, Justin's emotional strength has no bounds. Reflecting upon his disability, Justin attributes it to providence. "The way I see it, I was born into this, so it's really not that hard to remain positive. Being positive creates a healthy energy. I've never really let anything get in the way of my singing. My passion for music is too powerful." So powerful is his love of music, in fact, that Justin views it "as essential as breathing. It's so hard to describe what music means

to me. It's a source of so many things like healing, communicating to people, and love."

The launch pad

As a youngster, it was Justin's grandmother and parents who nurtured his musical talents. "My grandmother took a keen interest in my singing early in life. She really was the driving force in helping launch my career. She had me performing in front of family, friends, community events and church by the time I was five. My father played folk

guitar while my mother is blessed with a wonderful voice. They were selective when it came to showing it. We never played music together on any regular basis – we certainly weren't The Partridge Family or anything like that – but when we did, it was special because it was so rare."

Justin is particularly grateful for his older brother's childhood grace in the face of a sibling who perpetually took center stage. "It must have been an interesting road to have to live with a brother like me, always getting special attention for my disability, and then being in the spotlight for my career," says Justin of Brandon, now 32. "I can't imagine how he must have felt growing up. It's amazing [Brandon] never showed any resentment; we've always been best buddies. I can't ask for a better big brother."

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¹ A hardening of the tissues in the nervous system and particularly of the brain and spinal cord that results in nerve cells' degeneration.

There was another musical influence in his life; something that remains a cherished part of Justin's early memories: "We had a jukebox in the house that constantly played my father's old 45s. I would listen to Jim Croce, James Taylor and Cat Stevens for hours and hours. I ended up being so attached to the jukebox that I stopped my father from selling it when he was thinking about doing so. It's still here in the house and I listen to it from time to time."

Justin has been composing his own lyrics and music since he was a teenager. "I was cowriting when I was 15. The following year I began writing my own stuff," he recalls. His efforts paid off in the culmination of his first project in 2007, when he produced and released his first album, *Sides*, in collaboration with guitarist Justin Abedin.

In pursuit of dreams

As a student, it was the challenge of balancing his career and schoolwork that stands out most in Justin's mind as the greatest hurdle he had to overcome. "I never really had to put up with kids teasing me. The most difficult thing for me was dealing with a growing career that coincided with high school. I never really got to experience high school to its fullest extent. I was constantly pursuing media opportunities and working on something related to music."

In his quest to break into the business, Justin missed more than his share of school. For this aspiring artist, however, skipping a few classes often meant the difference between "making it or breaking it" in the music world. On a ride to school one morning when he was 13 years old, a local Top 40 radio station invited listeners to showcase their singing talents at the Metro Toronto



Justin through the years (clockwise): At age 4 with his mother, Carol; age 8 with his dog Mindy; and age 3 with his brother, Brandon.

Convention Center. Seizing the chance, Justin detoured to the center and was the first to audition among hundreds of contestants. The very next day, he learned he had won the prize: an opportunity to sing the national anthem at a Toronto Raptors game before 17 000 people.

A remarkable achievement by any standard, Justin was nevertheless

uncertain of the direction he would take following his introductory performance. "I wrote a song for the new millennium and sorta just sat on that," he recalls. "Herb Gray, who was Canada's Deputy Prime Minister at the time, heard the song, and before I knew it the Government sponsored me to do 10 shows at various galas. At one of [them] I sat next to Prime Minister Jean Chrétien."

That experience gave Justin a new sense of direction. He took a few years off and eventually produced *Sides* in his home studio. He even learned to play the piano and keyboard, despite having only seven functional fingers. It was around the same time that Justin got his second big break – the break that catapulted him into stardom. Shortly after signing on with The Orange Lounge Recording Company, a song from *Sides*, "Wish You Well", was pitched to Walmart's Walk for Miracles, which raises money for children's

hospitals. Walmart picked the song for one of its campaign commercials in 2007 and again in 2008. As Justin puts it, “things kinda got rolling from that point on for me.”

Rising to the top

Today, Justin has tuned in to what he calls “the art of being in the moment,” which he defines as the ability to “find meaning in the simple things in life.” Judging by the popularity of his latest album, *Chasing Silver*, it appears Justin is a master of “being in the moment.” Released in March on iTunes and in music stores nationwide, the album’s single “Say What You Will” was the number one downloaded singer/songwriter single on iTunes in Canada for seven weeks running.

Chasing Silver is a captivating musical journey filled with evocative imagery and introspective lyrics aiming to

provide listeners with a truthful and honest account of Justin’s world view. While his universal message shines of idealism, he has always been realistic about his goals and limitations. “I knew I wasn’t going to be a pitcher for the Toronto Blue Jays. It has nothing to do with setting up road blocks for yourself but more of a case of putting yourself in the best position to succeed.”

Justin has certainly achieved success; *Exceptional Family* notwithstanding, he’s been on the cover of several magazines including *Macleans*, *People* and *Canadian Living* as well as the *Toronto Sun* newspaper. No less impressive is his list of awards. “I’ve won a few,” he says, proudly. “The most recent and biggest to date was in March. I won the Factor Breakthrough Artist of the Year at the 2009 Canada Radio Music Awards (CRMA) in Toronto. There was the Roger Abbott and Don

Ferguson Easter Seals’ Award for Achievement in the Performing Arts, which I won twice – first when I was 15 and a second time 10 years later. Last but not least, I won the YTV Achievement Award back when I was 16. Oh, and I was also nominated for a Gemini.”

Paying it forward

If there’s one thing that rivals Justin’s love of music it’s his incredible drive to help others. Well before his singing career took flight – at age 10, in fact - Justin co-founded an organization together with JAD Media, his management company. The Justin Hines Foundation aims to “focus on one’s abilities rather than disabilities. It’s not just about raising money but about awareness as well. It’s about being creative. Each charity campaign has been different.” In addition to Walmart’s Walk for Miracles, Justin has lent

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his support to organizations like Variety Village, a Toronto-based children's charity. "I'm just happy I'm in a position to help people," he says. "I find it really cool to be able to use my music to spread love for the greater good. Yes, it's a little ambitious, but the overall aim is to help people. The beauty is that music allows me to be creative while increasing awareness for issues I consider important. For me, this is inspirational stuff."

As if a career in music and supporting the Foundation weren't enough, Justin is also active in promoting the Paralympics. Together with 11 other artists, Justin participated in a series of concerts commissioned by the IOC at the Beijing Olympic Games in 2008. "The concerts took place between the end of the Olympics and the start of the Paralympics. My experience in China was really interesting. I got to work with artists like Sheila E. and Oliver Jones. Here in North America, the Paralympics are an afterthought. In China, the media coverage was just as intense as the games themselves. Hopefully, we can bring the exposure the Paralympics deserve here."

When he's not performing, raising funds and/or awareness for an organization, or helping out at the Paralympics, Justin serves as a motivational speaker. "There's no specific demographic I focus on. I give talks and offer advice to companies and schools and everything in between. It's unique because in between talking I actually sing some songs. It's certainly something I love doing."

True to himself and the value he accords to "being in the moment", Justin finds satisfaction in every aspect of his career. "Some artists don't like certain things about the

business, like giving interviews or getting in the studio to record. I love everything connected to this career.



PHOTO: RON BOUDREAU

It gives me a full sense of my purpose and new perspectives each time I speak with people."

Dealing with a disability is something Justin will never be able to escape, but nothing will dissuade him from pushing forward with

his plans. As a sports fan, Justin sees a great lesson in baseball legend Jackie Robinson who was the first African-American ball player to break the colour barrier in 1950 for the Brooklyn Dodgers. "There was a quiet dignity and resolve to Robinson," Justin notes. "Breaking through preconceived notions is tough, but as Robinson showed, not impossible. His was a powerful message of, 'don't judge me on the colour of my skin but on my baseball skills.' Similarly, I don't want to be judged on my disability but on my singing."

For Justin Hines, being blessed with a beautiful talent isn't a means to an end. It's also about the process; about changing lives and helping people through the power of music, one note at a time. ■

To listen to Justin Hines' music, visit www.justinhines.com. To learn more about his foundation and charitable endeavours, visit www.justinhines.org.

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Regaining Control of the Ship



Helping Frazzled Parents to Manage their Children's Behaviour

by RICHARD SELZNICK, Ph.D.

The landscape of modern parenting is very different from previous generations. Within the past 20 years of practicing as a child psychologist, I have seen significant changes in the parenting styles of the parents coming to see me. Modern parents tend to employ methods based on thoroughly researched theories; they have read many of the top psychology books, visited parenting websites, and approach their roles in a carefully thought out manner. In short, parents have many more concepts and ideas which they freely refer to when it comes to the management of their children's behaviour.

In spite of their increased knowledge and understanding, many parents still find themselves quite frazzled and overwhelmed by their children's often difficult and demanding natures. As one mom recently confided about her challenging five-year-old, "You don't understand – I'm a prisoner in my own house. It's like living with a terrorist. He is relentless."

One of the theories fueling such desperation is the notion of a "child-centered household." In such households, the parents effectively revolve around the child, attending to his or her every need and desire. When I listen to child-centered nightmare descriptions like the mom's

above, I imagine the child acting like the queen in Alice in Wonderland – continually issuing demands while the servants scurry in every direction. If the servants don't please the queen, it's "Off with their heads!"

While you may be thinking that your own household is not quite as unruly or extreme as this, you may still be contributing to your child's behaviour challenges unwittingly by catering excessively to his or her demands. In my own practice, I have found that modern parents are often unaware of the extent to which they yield to their children's dictates - often to their kids' (and the entire family's) detriment.

Some of this parenting style may constitute a response to the perception that parents of previous generations were somewhat detached and not as involved as they should have been with their children (the parents of today). The modern parent thinks to him or herself: *I'm going to be different than my parents were with me. I am going to be very attentive to my child.* Such attentiveness, while wonderful in many respects, has its downside. When the hierarchy of the family is upended and children are in the center, this typically leads to a great deal of anguish in the household, often directly felt by the moms. Without generalizing, it does appear from the families I see that moms are more on the frontlines versus dads when it comes to managing their children's day-to-day behaviour. As a result, mothers tend to feel very overwhelmed and, sometimes, hopeless.

Different parenting styles also contribute to many of the issues that are seen; "Peace-making Parents," for example, can't handle too much negativity from their children, or within the family dynamic as a whole. They want their relationship with their children to be nice, smooth and completely devoid of friction at all costs.

"Over-Intellectual Parents" reason through everything and are the child-rearing "experts" who know exactly what should be done in every situation. However, they are often not particularly effective in taking action when it is needed to make an impact. "Blasé-Style Parents" are somewhat disconnected and insufficiently engaged with their children. They can let a great deal go without

much commentary in terms of attempting to correct or change their children's conduct. "Defensive/Not-My-Child Parents" see fault in



When children are in the center, this typically leads to a great deal of anguish in the household, often directly felt by the moms.

everyone else but their own children. These parents are often quite combative with teachers and challenge school administrations when approached to deal with any challenging behaviours that may have been exhibited by their children. "Guilty-Style Parents" are overwhelmed by their senses of having made the wrong choices. They continually worry how their choices are

negatively impacting upon the child. The classic example of parental conflict centers on the decision to put the child in a daycare setting.

This feeling is often conveyed by moms in my office who express a constant sense of guilt around having/choosing to work during their children's preschool or elementary years. Such guilt can result in a great deal of excessive indulgence of their children and the provision of pleasure at all costs, including tossing discipline or behaviour-management out the window.

You should examine your own parenting style without getting down on yourself if you feel that your child's behaviour has gotten a bit out of hand. Sometimes it's helpful to talk to someone who is a bit detached from the situation, such as a counselor or therapist. He or she may be able to provide you with valuable feedback and suggest behaviour-management techniques as well tips to improve interactions with your child. Additionally, the following guidelines may help assist you to regain control of the ship:

Avoid the favourite and most frequently employed parenting method: yelling. When was the last time you yelled at your child and he or she responded with, "Thanks Mom, I understand. I'll stop behaving that way"? Right – never! Yelling rarely works, yet it is the single most used parenting method in the vast majority of households. While shouting may be an improvement over hitting the child (a preferred parenting tool of previous genera-

tions), it is simply an ineffective discipline tool since it rarely changes the child's behaviour and almost never leads to learning on the child's part. When a parent yells, the child acts defensively and rarely considers what he or she did wrong.

Anticipate and exercise your immediate leverage. Parents often use threats of delayed punishment that consistently fall on deaf ears. This is because the consequences are not imposed instantly and as such are beyond their kids' immediate emotional frame of reference. For example, prohibiting your child from attending a birthday party on Saturday when she misbehaved on Thursday may have no impact on increasing the child's compliance. Yet, parents often issue such threats, thinking that they will improve behaviour.

By being aware of your more immediate leverage, the discipline you implement will not only have a greater impact, it may even yield better results in your child's willingness to cooperate in the future. Suppose, for example, that your

child is eagerly anticipating an upcoming soccer game. On the day of the game, however, he dawdles and is completely uncooperative when it comes time to leave. Using a calm voice and very objective, straightforward tones, you may wish to say, "Gee, I'm sorry you're not cooperating. It's really too bad that you're going to miss so much of

the game." If your son continues to dawdle, continue to utilize "that's such a shame" statements.

Too often, parents are much too concerned about hurrying out the door with a non-cooperative child in order to arrive at a destination on time, instead of letting the child experience the effects of his or her choices. Of course, if the child has no interest in going to the soccer game in question, using that

particular event as a consequence would have no leverage in terms of affecting his or her behaviour. This is why you must continually stay on your toes and anticipate leverage as it is constantly changing.

It's ok to let your child experience the repercussions of his or her actions. Often we are too quick to

Negative behaviour catches our attention. However all kids – and particularly those who are challenging – require positive feedback when they are doing the right thing.

let children off the hook. "Let him stew in his juices" is an old expression that refers to allowing a person to feel the guilt if he or she has done something wrong. A child learns from feeling the sting of bad actions or choices. I find many modern parents have lost the art of this approach with their children. Instead, they are overly fixated on the long-term psychological implications of the child feeling bad about making a poor choice or behaving poorly. While I would not advocate excessive "stewing", a good old-fashioned dose would not constitute the end of the world. In the process, the child will learn that his or her behaviours have consequences. Maybe he or she has hurt your feelings and you are not going to be so quick to be the all-nice and giving mom. It's ok. He or she will come around. Moreover, your child may even apologize – and mean it!

Catch your child being good. Negative behaviour catches our attention. However when children behave appropriately, their behaviour is often ignored. While it's human nature to respond when your child is acting out, all kids –

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and particularly those who are challenging – require positive feedback when they are doing the right thing. Punctuate a good experience with a spontaneous comment like, “Wow. You were really great in the store. You followed the rules beautifully. When we get home, you’ll get a marble” (see next point). Social praise such as this is one of the most powerful ways to reinforce behaviour in a positive way. Be specific to the behaviour that has occurred. Watch overdone praising, however, as children learn to tune it out.

Reward with tangible reinforcement whenever possible. While I am not a big proponent of elaborate behavioural systems (such as points accrued for good conduct) because they become unwieldy and difficult to manage, I find the use of an inexpensive object like a marble awarded to the child after the accomplishment



of a set goal or activity (such as behaving at the store or cleaning up, for example,) is a fun, tangible reminder to the child of having made the right choices. Most kids

like marbles and seeing their jar fill up serves as a motivation for them to act accordingly in the future. Do not give them a complete bag of marbles ahead of time, however; each one must be earned. Additionally, do not link the marbles to monetary rewards, as in, “When you earn 20 marbles, we will go buy the video game you want.” Better to surprise the child with a small non-monetary experience: “Wow. You’ve earned 20 marbles! Let’s go celebrate with an ice cream cone.” Monetary rewards such as video games do not provide the same shared experience of celebrating the success as going for a treat with their parent has. It’s the fun of doing something together positively with their parent that conveys the right message to children

– the message that you endorse and appreciate their good behaviour.

Children’s behaviours can be quite challenging, particularly if you have a child who is on the difficult side. Watch the hierarchy of command in your home, check your parenting style, and try practicing a few of the aforementioned skills. By making little changes, you will find your own battery won’t be too depleted. Most importantly, take it slow – change does not happen rapidly. ■

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



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Ask the Expert

A Painful Adjustment to a Positive Development

Q After over two years of waiting for a spot in a particular early intervention program for our five-year-old daughter with autism, we finally got a call last spring that a space opened up for the upcoming academic year. The program began two weeks ago and runs daily from 9:00 to 3:30. My husband and I are elated and relieved that all of our daughter's needs are finally going to be met under one roof and she seems to be adjusting to the new routine. The only one who isn't adjusting well is me; as my daughter's primary caregiver for the past five years, my life literally revolved around her. More recently following her diagnosis, my days were filled with everything from driving her to and from therapies and implementing interventions at home, to orchestrating play-dates and even cooking meals related to her specific diet – a diet her new multidisciplinary team has discontinued. I now find myself literally twiddling my thumbs and looking for ways to fill the hours. I hate to admit that a part of me wishes the space had never opened up. My husband doesn't understand why I can't just "enjoy my freedom." I never thought I'd feel so useless and aimless at 43.



PHOTO: LAWRENCE CLEMEN

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

A Congratulations on having fulfilled a long-awaited plan to maximize your daughter's potential. As you mention, despite feeling elated and relieved, you are finding the adjustment to what is for all intents and purposes a positive development, to be painful for you.

I think it would be fair to say that virtually all change carries with it some degree of mixed emotion. Whenever we open a new door, a door behind us closes, so to speak. As we find ourselves standing on the threshold of the unknown we struggle to maintain our balance between the safety of familiarity and the uncertainty of new opportunity. It's not that we necessarily want to go back; it's just that we are not yet up to speed on the adjustments that moving forward will be calling upon us to make.

Throughout the normal course of development we are continually challenged to let go of one stage of life in order to proceed to the next. Most of us identify with the memory of having to leave our parents' sides to set off for school, and in turn, having to let our own children leave our sides as they begin to take those steps into their own futures which no longer include our physical presence. And, somehow we all live to tell about it. But what of the particular course of development that your own life cycle has taken with the arrival into your life of a child with special needs?

A whole different set of circumstances prevail as exceptional parents begin

to contemplate their responsibilities and their futures. Like the majority of parents in your situation, you knew from the moment of diagnosis that this child would need you differently and would never simply move through the predictable stages from dependency to autonomy. In a very real sense you committed to





sacrificing your own life. And now that it has been returned to you, at least in part, it must feel as though you have been “fired” from a job that you have done so well.

Virtually all change carries with it some degree of mixed emotion. Whenever we open a new door, a door behind us closes, so to speak.

Here are some practical and psychological suggestions in terms of what you can give yourself to help ease what is understandably a major life transition for you:

Give yourself time to grieve. All change is difficult even when it is positive and carries with it the embodiment of our wishes. Life transitions are no exception. You are grieving for the loss of a role which you have been fulfilling these last five years, a loss which is still very fresh. You are entitled to your feelings of sadness, regret and aimlessness which are normal for the time being.

Give yourself credit. You have been providing your daughter with what sounds like every possible advantage to facilitate her progress, from implementing therapeutic interventions to managing her specific diet. Your dedication is praiseworthy. The fact that she is moving on does not undermine these accomplishments but rather, it is a testament to your perseverance.

Give yourself perspective on your mothering role. That part of your



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identity which you take from your mothering role still exists. Although your instrumental functions may be different in terms of the daily routine, you remain central to your daughter's world. She continues to need and value you as an ongoing source of love, support, caring and encouragement.

Give yourself a broader self-definition. Your functions as an exceptional

parent have been so all-encompassing that, not uncommonly, your definition of "self" has become skewed toward this singular role. It is time to contemplate and redefine your identity through a wider dimension. Ask yourself "who else" and "what else" you are, in addition to the mother of a child with special needs.

Give yourself the opportunity for personal growth. Your newfound

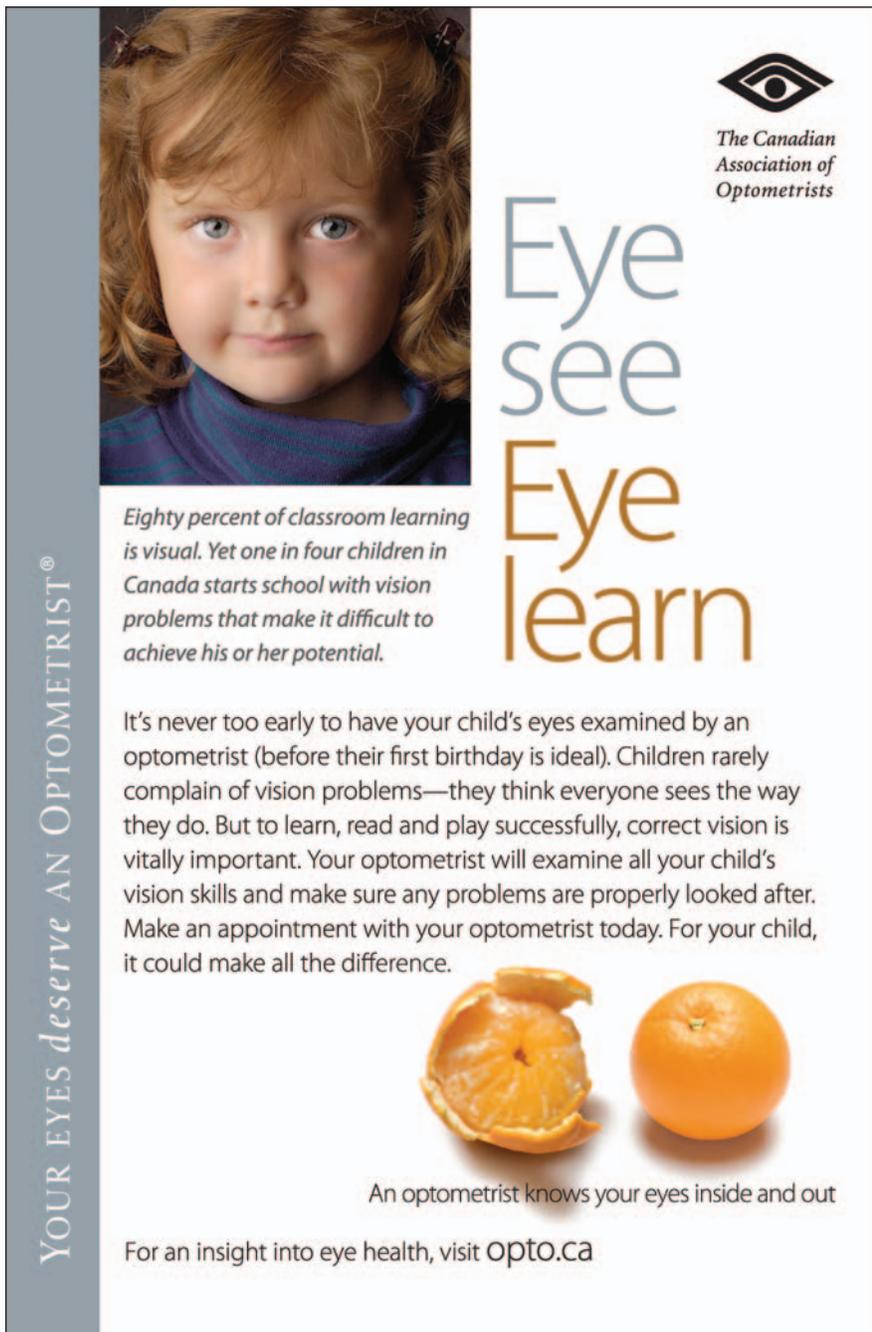
freedom heralds the opportunity to revive yourself outside of your caretaking role. Reflect on some of the goals and plans that you may have had to forsake while managing your daughter's priorities. These may range from taking some time to get in physical shape, to pursuing a hobby, a program of study, or part-time employment.

Give yourself permission to relax. When your engines have been revved up, it is hard to slow them down. Having expended such constant energy on your daughter, it may feel like you are unproductive if you don't fill every spare moment with activity. Why not take advantage of the chance to enjoy a leisurely stroll, lose yourself in a good novel, or take in the latest museum exhibit now that your pace of life is less frantic?

Give yourself the gift of renewed relationships. While you have been focusing on your daughter, it is likely that others such as your husband, extended family and friends have been waiting on the sidelines for more inclusion. Your expanded personal development and the reestablishment of intimacy and social and emotional connections need to work reciprocally to enrich your 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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The David Roche Beauty School

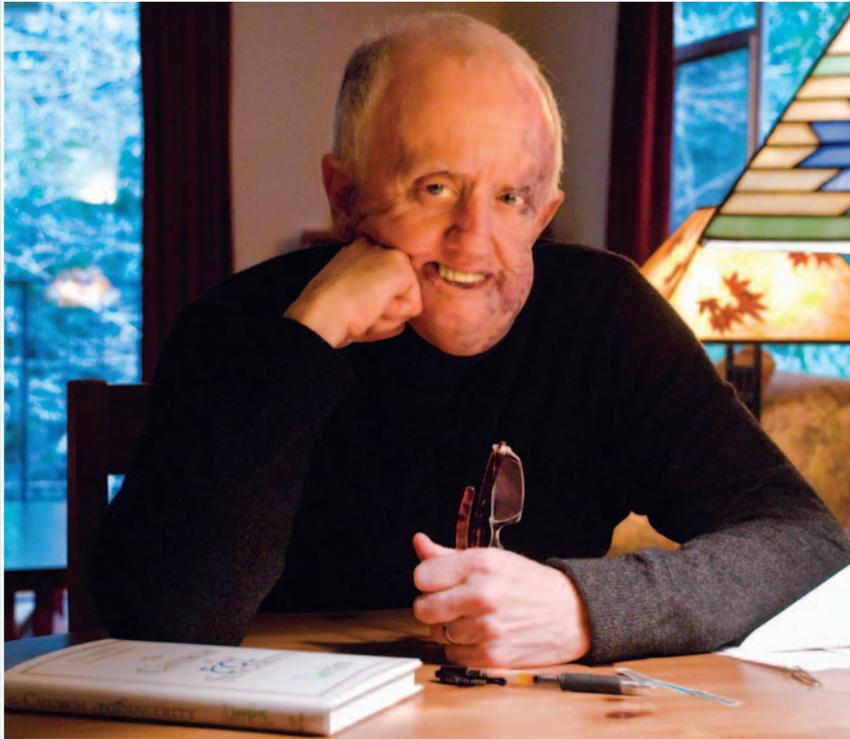


PHOTO: JAMES HALL

by DAVID ROCHE

In the Grade 6 classroom at Creekside School, I impulsively announce the founding of the David Roche Beauty School.

Who am I to found a beauty school? My main qualification might surprise you: I am facially disfigured. A vascular malformation lives, purple and bulging, on the left side of my face and neck. I am from the generation of denial, and for over 40 years did not talk about my appearance. In my middle years, I found my voice and since then have made a living as a performer, keynote speaker and author. Along the way, I've learned that my face is unique but my experiences are universal — in other words, everyone feels disfigured or disabled in some way. And everyone needs to find their inner self, the source of their individual beauty.

Those of us with facial difference understand this because we have been forced to look inward to find the true source of our beauty and self worth. I feel most useful when I bring this understanding into my work; particularly when my wife, Marlena, and I present our “Love at Second Sight” program to youth on the cusp of puberty with all its accompanying fears about appearances and acceptability. Marlena and I appeared last year at Creekside School, so when the principal invited me to drop in on the Grade 6 class, my face was familiar to them.

Editor's Note: What follows is the exchange between David and the students. David's comments are in bold and the students' are in italics.

“Kids, I want to hear who you think is really beautiful in your life.”

The students jump in immediately. Laurie, with black hair and black-rimmed glasses, has her hand up before I finish the sentence.

“Frank is beautiful – my Chihuahua, Frank.”

I am a little surprised but the other students are not. Three others raise their hands when they hear this.

“My pit bull!”

I'm sure I look a little bit astonished.

“Your pit bull? So, tell us how your pit bull is beautiful.”

“Well, when I lay down on the couch, he comes and lays down behind me...” She gestures to her back, glancing at students nearby to see if they get the visual. They nod. *“And he pretends to stretch, you know, but really, he is pushing me off the couch. And that is beautiful.”*

I laugh. **“I see. That sure is beautiful.”**

In the front row, Trevor raises his hand. Last time we were at Creekside, he

announced to the class that he has Fetal Alcohol Spectrum Disorder. I thought that meant he might have difficulty interacting with others, yet he has a vibrantly warm personality.

"My bunny, Honey Bunny. He is so beautiful."

I look around. I am worried that he will get teased for this answer. Not so. More hands are in the air. They are totally rapt and into the exercise.

Megan has a round face framed with strawberry blonde hair. *"My grandma. She has had two strokes but she still cooks dinner for us every night and she won't sit down until we have started eating. I think that is beautiful."*

"Oh, a beautiful person. Thank you. Good. She sounds very kind. I think kindness is a sign of beauty, don't you?"

They all nod yes.

"Who do we know in this room who is kind? Let's have some kindness nominations."

"Nancy is kind."

"Who is Nancy? Is she here today?"

Half of the class points at Nancy, who responds by drawing in her shoulders, staring down at her desk and flushing.

"How is Nancy kind?"

"She always says hi in the hall every morning."

"Friendliness," I say. **"That is a sign of kindness."**

The girls continue to lead the way.

"Brianna. When I don't feel good, she asks me if I am ok."

"Kate. She took me to the school nurse when I got hit in the face with a basketball."

I intercede. **"Now I want to get the guys involved. I want to hear kindness nominations about boys."**

They are ready. They just had to be asked.

have chosen a word other than "beauty". But they certainly get the kindness part.

"Daniel is kind because he always helps us in art class and shows us what to do so it is easier."

Daniel's head pops up. He is a little guy with a punk hairdo, carrying an air of



PHOTO: VINCE MAGGIORA, SAN FRANCISCO CHRONICLE

Longing for more – middle-school students in Fairfax, California surround David Roche after one of his inspiring school talks.

"Sean is kind."

"How?"

"Umm, he shares his dirt bike. And his Wii."

"Wow, sharing your dirt bike! That is something special. Sharing is certainly a form of kindness and that is really beautiful."

Another: *"Gord, because when I am playing soccer and make a mistake, he tells me it's ok, and then I know it is."*

I am astounded at the depth of what I am hearing.

The boys tend to be more impassive when acknowledged. Perhaps I should

toughness and bravado. I never would have thought him to be an art angel. He looks startled. I suspect that kindness is not a big part of his self image.

"Two good examples of kindness that is beautiful. Someone who encourages you when you are down, like when you make a mistake. Especially in sports, right, guys?"

The boys nod. A couple of them have small, wry grins.

"And being helpful in art class, yes. I wish I had someone like you to encourage me, Daniel, when I was your age."

Megan has her hand up again and is looking at me expectantly. I call on her.

"Well, I have acne and some people think that is weird, but my friends don't worry about that."

I am amazed at her straightforwardness, her calm tone of voice.

"Are your friends here?"

Megan points across the room: *"Sofia. Claire."*

I look in the direction of her gesturing. **"Sofia, is that true?"**

Sofia lights up. *"Yes."* I look at Claire and she smiles.

"Yes, looking at who someone really is on the inside is beautiful. Thank you. And thank you, Megan."

Tom, in the front row, raises his hand six inches from his lap, then jerks it down. He is hesitating. **"Go ahead,"** I say.

"Well, I can be pretty wild and some people think that is strange, but when I came here I did not act that way until I met Patrick and he is kind of wild too, so we got to be friends and now I act wild and I like it."

Our time together is winding down.

"Thank you all so much. This has been –" Laurie is waving her hand.

"Ok, Laurie, one more."

Laurie takes control of the class: *"Who hasn't been nominated yet?"*

They all look around and point at the kids who haven't had their kindness acknowledged. They start in again without my participation. They want to finish the job. They do. Everyone gets a kindness nomination. Everyone. Even Mrs. MacDougall, the teacher. And they are sincere acknowledgements, not phony at all.

Now it's lunchtime and there is no putting that off. I have to leave.

"Thank you for helping me start the David Roche Beauty School."

A couple of them applaud. Most of them jump toward the door and lunch.

On the drive home, I already miss the students fiercely. That was so much fun. I am proud and excited about

the launch of the David Roche Beauty School. But I start wondering.

How can you tell whether someone is beautiful? I like this question. Maybe it should be: What are the ten best signs of beauty? Is kindness really one of those signs (or was I just pushing that on the kids)?

Well, I thought, kindness would get my vote. Maybe that could be an introductory course in the David Roche Beauty School. We could address important questions like: How do you encourage someone when they make a mistake in sports? How do you tell when someone needs encouragement? Is it difficult to be kind? Where do you learn to be kind?

I wish I had pointed out to the kids that all of their examples were of inner beauty (except maybe for Honey Bunny and Frank the Chihuahua). That we all want to look good, but what people truly care about is how we act.

It strikes me that it might be difficult for them to recognize human beauty, that they need help and encouragement to do so. Maybe that is why they were so into the kindness nominations. Because they are eager to learn about this. That is something the David Roche Beauty School can help with.

I slip out of self-improvement mode, sigh, relax in the beauty of the day and exult in the moments of grace the kids have given me. ■

David Roche is an internationally known inspirational humourist and author who lives on the Sunshine Coast of British Columbia. For more information, visit www.davidroche.com.



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THE SAFETY BED

As we jump into year number 5 at Exceptional Family, we're proud to share samples of reader feedback from the past year. Our thanks go out to all who have taken the time to communicate. Keep those e-mails coming! Drop us a line at feedback@exceptionalfamily.ca

I would like to thank Exceptional Family for the recent article about my work with The War Amps and its Child Amputee (CHAMP) Program...Please accept my congratulations as well on an excellent and informative magazine.

Cliff Chadderton, CEO,
The War Amps, Ottawa, ON

I am very impressed by the excellent calibre of articles that appear in your magazine. It was no surprise to me to hear that you have won awards...Congratulations on a wonderful and helpful magazine.

Toby Shainbaum-Pollak
Chef D'Équipe – D.I. TED, CLSC de
Côte-des-Neiges, Montreal, QC

I received your Fall issue and enjoyed reading it from cover to cover. Great job!

Karen Congram, Stratford, ON

I recently received your Winter 2008 magazine and read it with interest and enjoyment. Thank you so much for this wonderful resource for Canadian parents of exceptional children!

Karen Obukoru, Queensville, ON

Congratulations on a terrific magazine; I have been a subscriber for 2 years and am extremely pleased with your work.

Maria Colavita, Pierrefonds, QC

It was wonderful to find a magazine that contains such varied coverage of exceptional children and their families. I also appreciate that the content is Canadian.

Andrea Cameron, Brockville, ON

[Exceptional Family] has become a permanent fixture on our coffee table – and we have been encouraging friends/families to subscribe.

Hal Newman, Managing Editor,
Big Medicine, Montreal, QC

The magazine is absolutely amazing cover to cover. I have provided a copy to each of my boys' schools, which have shown interest in subscribing as a resource for their staff/parents. Exceptional Family is an excellent resource for educators...a wide range of disorders/disabilities is featured, providing a wealth of information globally. A definite asset in our growing culture of integration. Also

a key resource for information-sharing with parents new (or seasoned) to disabilities/disorders.

Bernadette Pace, Niagara Falls, ON

I recently received a copy of the Winter 2008 Exceptional Family magazine and I found it to be a fantastic publication. I was also very proud of the article by one of our very own ("Words Hit Like A Fist", by Dave Hingsburger)...Keep up the great work; we ALL need some help and inspiration.

Paul J. Mior, President,
Vita Community Living Services,
Toronto, ON

I was very moved and inspired by the article on inclusive dance in the Spring issue (Vol. 4 No. 3, "So You Think You Can Dance? Well, So Do They!"). I am the father of a 22-year-old man who has a profound intellectual disability. My wife and I took up Latin dance to do something for ourselves after years of near-complete focus on our son's needs. This was a very healthy move for our marriage (and for our ability to sustain our relationship for our son). In February, we organized a fundraising dance in honour of exceptional families. We expected 100 people; over 350 came, many of them with exceptional children. One of the most tender and amazing moments occurred when two friends in their 20's – one of whom has Down-syndrome – moved to the centre of the dance floor where they gyrated and flipped to Michael Jackson's "Beat It" amid onlookers' cheers and calls for an encore. Dancing their hearts out, those two young men were absolutely awe-inspiring.

Donald Bidd, Montreal, QC

I had decided I would not renew but after today's issue (Vol. 3, No.4) I am! I loved the article for us grandparents... I loved the article about religion and special children...The toilet training article was good too and showed me how much patience and planning is needed to accomplish one task for an ASD child!

Cari Grierson, Kincardine, NB

I want to take this opportunity to thank you and the staff of Exceptional Family for the exceptional magazine you all produce. We now purchase it for our families as they wait in our waiting areas, knowing they will have an opportunity to find Canadian information on a topic of particular relevance to them. Your articles are always of a high professional calibre.

Kirstie Glasgow, Director of
Occupational Therapy and Next Step
Autism Program, Fraser Valley Child
Development Centre, Abbotsford, BC



Lovely Imperfection

by BARBARA BYRD

My granddaughter, Cheya, recently turned two. Of course we honoured her birthday with a cake and presents as loving family members gathered round. Her first birthday was the truly meaningful one, though, because my daughter, Amanda, had been practically guaranteed by the doctors that it wouldn't happen. Amanda had circled the date with a red marker on the calendar, anticipating that day as "a red letter day" for our family.



Cheya at 20 months, prior to surgery.

Even before Amanda became pregnant, I had fantasized about the incredible child my daughter would one day produce. Amanda is an exotic blend of biracial beauty inside and out; the product of a Jewish mother and Black father. Her coffee-coloured eyes are wise and penetrating. Her skin is creamy caramel, her lips full and sensuous, but it is her intellect that has always been staggering and has won her many accolades. Amanda married a talented artist. I was certain their child would be an amazing specimen – beautiful, artistic and over-the-top brilliant.

I pictured myself reading and singing lullabies to my grandchild, and the two of us connecting with our eyes and hearts. Any regrets I had had about raising my four children as an impoverished single mother would be

corrected with this new-generation baby. I would buy educational toys and cute clothes, and he or she would be bathed with love and support by a large, adoring family.

On the much-anticipated day Cheya was born, my other daughter, Rachel, and I went to the hospital upon hearing the news. Amanda had just given birth by C-section after a prolonged labour. My son-in-law stood outside the doors that led to the maternity ward. He looked gravely serious but, in my enthusiasm, his expression barely registered. "How's the baby, and how's

Amanda?" I asked, more as a formality, assuming they had to both be fine; after all, Amanda never smoked, never drank to excess and not at all during her pregnancy, was not a drug user, ate well, and had secured good prenatal care. It was time to hold my precious grandchild in my arms and congratulate my daughter for her amazing feat.

I can't recall my son-in-law's exact response, but he managed to convey that the baby had been born with a cleft palate and malformed nose. Cheya weighed 8lbs 8 ozs, which should have meant that she was strong and robust, but she was in the NICU attached to tubes. An MRI had revealed that she had severe brain damage.

I burst into tears and my son-in-law put his arms around me. Rachel seemed too stunned to react at all for a moment, and then the word "Mom" escaped from her lips preceded by the sound of her sobbing. A moment later Amanda was wheeled out of surgery, her face an unreadable mask, her eyes not meeting those of her grieving family.

Cheya remained in the hospital for several months.

Two years after this bittersweet day, Cheya doesn't sit up, but she smiles on occasion, usually when she gazes into the face of her amazing mother. While the doctors didn't know at first whether Cheya could see or hear, she can do both. She had surgery on her mouth at around 20 months and although she still looks physically anomalous, she's actually quite pretty.



Cheya following her corrective surgery.

These last two years have gradually brought me to a place of acceptance. I see Cheya often, and I value her for who she is. I don't compare her to my three other grandchildren.

Amanda has been a remarkable and resilient mother from the beginning. She is fiercely protective and loyal to her daughter. I'm reminded of a particular incident where Amanda's valour shone through. Prior to Cheya's corrective surgery people would sometimes do a double-take when they saw her, and they wouldn't always be discrete about it. On the occasion in question, Amanda and I were entering a local mall together when she ran into an acquaintance. It was cold, and Cheya's little face was covered. The young man asked to see the baby and Amanda, without hesitation, pulled the blanket from Cheya's face, so he could see her. I noticed the shock in his eyes before he was able to cover it with a nonchalant mask. *How could she do that?* I wondered, certain that I would have kept Cheya's face covered in public. *How could my daughter be so brave?* It was at that point that I realized I would have been ashamed of my own baby,

and I was overwhelmingly proud and relieved that my daughter had her priorities in exactly the right place. All that mattered to her was the welfare of her child. "I don't want people to make fun of her," she once confided. *Of course, she didn't!* Upon hearing that, one of many waves of grief washed over me. I mourned for my grandchild and for my child even more, because teasing probably won't matter to Cheya, who likely will never be able to pick up on those nuances.

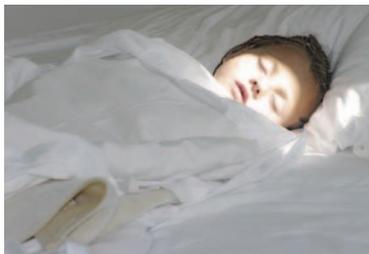
These last two years have gradually brought me to a place of acceptance. I see Cheya often, and I value her for who she is. I don't compare her to my three other grandchildren, one of whom is Cheya's six-week-old sister, Kellice. I don't even bother to set expectations for Kellice as I once did for Cheya. My fantasies of having a "super" grandchild just aren't important anymore. A while back, Cheya was hospitalized for a week after a severe reaction to medication which targeted her laboured breathing. We all thought we were going to lose her. Even her faithful mother whispered to her daughter, "Just let go, baby." Cheya loves life though and she prevailed –

undoubtedly due in part to the safe cocoon of love that is woven around her each and every day of her life.

I have dreamed some beautiful dreams about Cheya. I believe they're from God. She has taught our family so much about what's really important, what really matters. Not so long ago I had all these glowing aspirations for my unborn grandchild. Now I'm just grateful that she has lived another day. When she looks deeply into my eyes, I truly believe that the soul that resides there loves and knows she is loved in return, and that is enough. ■

Forsaking kids' forty winks a recipe for potential problems

Parents and caregivers who forgo their preschoolers' daily naps may be compromising the children's psychosocial functioning, according to findings presented recently at SLEEP 2009, the 23rd Annual Meeting of the Associated



Professional Sleep Societies, in Washington. Dr. Brian Crosby of Pennsylvania State University presented data on children ages four and five that had been collected by their caretakers over a seven to 14-day period. Of the 62 kids who participated, 77 percent napped while 23 percent did not. The parents of those who stayed awake during the day reported increased levels of hyperactivity, anxiety and depression in their kids, over those who snoozed. Recognizing that parents often terminate daytime napping in the hopes of lengthening and improving their children's nighttime sleep, Crosby suggested that the idea of ceasing naps at a specific age does not necessarily apply uniformly to all kids. He encouraged parents to institute a resting period during the day when their children may nap if needed.

Woman apparently doesn't look like a girl from Abercrombie & Fitch

A 22-year-old English law student is getting plenty of experience in her chosen field, having launched a lawsuit against retail giant Abercrombie & Fitch, which she claims discriminated against her because of her disability. Riam Dean was born without a left forearm and has been wearing a prosthetic limb since the age of three. Abercrombie's 45-page handbook outlining the store's "Look Policy" underscores employees' responsibilities to comply with the dress code and to reflect a "classic American style". Dean, who frequently sports a cardigan to conceal the site where her prosthetic begins, was permitted to add a white cardigan to her jeans and polo-shirt uniform. Two days into her part-time job, however, Dean alleges that a member of the company's "visual team" demanded she remove her sweater. Dean asserts that the manager then informed her that her cardigan violated company policy, and instructed her to relocate from the sales floor to the stockroom. Upon contacting the head office, Dean says she was asked whether she would be willing to remain in the stockroom until the winter uniform arrived. She is seeking the equivalent of US \$41,000 in damages.



New method to screen for premie eye disease holds significant weight



Swedish scientists at the University of Gothenburg's Sahlgrenska Academy have found a cheaper and quicker way to detect whether an infant is at risk of a potentially debilitating eye disease. Retinopathy of prematurity (ROP) frequently affects preemies and could lead to blindness if left untreated. According to Academy Professor Ann Hellstrom, while preemies typically undergo expensive eye exams to identify whether they require treatment for the disease, a more cost-efficient screening method would simply involve monitoring the babies' weekly weight gain. An increase in weight would signify a rise in IGF-1, a protein that plays a critical role in normal retinal vascular development. After comparing the weekly weights of 350 infants with their eye-exam results, the scientists discovered that the babies at risk for ROP had been identified as early as three months prior to having been seen by an ophthalmologist.

Teachers add bounce to their lessons

Canadian elementary schools are progressively replacing traditional desk chairs with exercise balls in the classroom with the primary goal of increasing students' physical health and attention. Backed by years of research including a 2006 Mayo Clinic study confirming the benefits of fitness-ball use in class, a number of Canadian schools are following the examples of their American, European and Australian counterparts and trading traditional metal and plastic chairs for softer stabili-



ty balls typically used for recreation and exercise. The findings reveal that sitting on the balls improved students' body-awareness, core and abdominal strength, balance, posture, and overall concentration. Teachers who incorporated the balls last year reported a greater sense of calm among their students, and cited the benefits the orbs provide for restless students in particular: whereas their previous fidgeting on noisy chairs would disturb fellow classmates, they may now let off steam by quietly bouncing or rocking on the balls. The colourful spheres typically measure upwards of 45 cm in diameter.

Communication impairment? There's an app for that.



A new application geared for people with communication impairments resulting from conditions like autism, cerebral palsy, Down syndrome, or strokes can now be uploaded on the iPhone and iPod Touch. Developed for individuals who do not have the ability to speak, the recently-released *Proloquo2Go* joins the slew of unique features like *Chinese Food Menu*, *Pet Vet Records*, and *SailorsWeather* already available on iTunes. The augmentative communication program emits text-to-speech voices, offers picture icons and contains a vocabulary of over 7000 items. In a recent interview with *USA Today*, co-creator Samuel Sennott, a doctoral student at Penn State, noted that his invention enables everyone to benefit from Augmentative and Alternative Communication (AAC) at a cost of US \$199 – an affordable price relative to those of most text-to-speech devices, which are prohibitive for many families. *Proloquo2Go* is not the only “app” geared for exceptional users; American Sign Language applications for the iPhone and iPod Touch have been available for upload for some time.

Technology brings “power of the mind” to a whole new level

A new technology that has proven successful in virtual reality holds tremendous promise for people with physical disabilities in the real world. Brain-computer interface or BCI enables people to perform daily activities like turning on lights, unlocking doors, typing, or channel-surfing, with their minds. As reported on the



ScienceDaily website, a group of international researchers affiliated with the EU-funded Presencia project recently demonstrated the BCI's application in a virtual, futuristic “smart home” – complete with a functional kitchen, bathroom and living room. According to Christoph Guger, CEO of the Austrian company that developed the technology, BCI users were able to move freely through the home simply “by thinking about where they wanted to go.” Users sported helmet-like contraptions with electrodes that came into direct contact with their scalps. EEG imaging recorded their brain activity and after a period of time, the system learned to distinguish the unique patterns of electrical impulses produced when users visualized themselves performing daily tasks. The BCI's transferability from virtual to real life has tremendous implications for people with mobility challenges, paralysis, or those with prostheses. Project coordinator Mel Slater suggested that wheelchair users may ultimately be able to control them with their minds.

Educating the Child with Low Vision in the Regular Classroom

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

by CAROL FARRENKOPF, Ed.D.

In previous issues of *Exceptional Family*, we delved into the importance of proper eye care for children, including early vision screening and signs of vision problems that may warrant further consultation with an ophthalmologist. We also explored the conditions of strabismus and amblyopia and highlighted possible treatments. With the start of a new school year comes the challenge of supporting children with low vision in the classroom. What follows are suggestions on how this can best be achieved.

“Low Vision” typically refers to a visual impairment that persists after best attempts at correction (i.e., prescription glasses or contact lenses) which affects the child’s ability to perform day-to-day tasks at home and at school. The degree of vision loss varies from child-to-child as does the way each child functions visually. For example, two children with myopia (nearsightedness) and the same visual acuity of 20/200 may “see” in very different ways — one



child may prefer bright lights in the classroom while the other child may prefer to have the lights off. The majority of Canadian children with low vision are educated in their local schools alongside their peers, while a small percentage of students may attend a specialized school (residential or day-program) for students with visual-impairments. In both cases, visual strategies and/or accommodations, assistive devices, and environmental modifications are used in the classroom to help children with low vision access the school curriculum.

Children with low vision, like their peers with sight, can participate in the regular “core” curriculum at school (e.g., English, mathematics, science etc.) as long as appropriate accommodations have been put into place. For example, if a student cannot see the decimals or exponents in a math textbook, he or she can use various tools such as a hand-held magnifier or a closed-circuit television (CCTV)/video magnifier to enlarge the print. Or, if a student with low vision has difficulty seeing the chalkboard because the blinds are open and the bright sunlight is creating a glare on the chalkboard, the teacher might simply offer to close them. Of course, some teachers — particularly in mainstream schools — may not always be attuned to the needs of children with visual impairments. In the case of the glare on the chalkboard, for example, a student might have to bring the problem to the educator’s attention — something that requires both self-confidence and self-advocacy; important skills that need to be taught.

The Expanded Core Curriculum

In order for a student to fully benefit from such accommodative strategies and tools, however, he or she must first learn which work well and how to use them. The Expanded Core Curriculum (ECC) is a set of disability-specific skills that are considered essential for children with visual

impairments (who may or may not have additional needs) to acquire.¹ These skills should be taught by teachers and other professionals who have been specially trained or certified in the field.

The ECC is comprised of the following:

1 Compensatory or Functional Academic Skills teach students how to communicate via additional media such as enlarged print and braille.

2 Orientation & Mobility Skills equip students with the proficiency and knowledge required to travel independently, safely, purposefully and gracefully though the environment, with or without a white cane or other mobility device.

3 Social Interaction Skills emphasize appropriate behaviour in situations that are difficult for students with low vision to learn incidentally or via casual observation.

4 Independent Living Skills instruct students in daily living tasks such as personal hygiene, time management, food preparation, and organization of personal belongings.

5 Recreation and Leisure Skills enable students to discover firsthand those leisure pursuits that,

with appropriate accommodations, can lead to a fulfilling life.

6 Career Education offers direct exposure to a variety of jobs that students may wish to pursue in the future.

7 Assistive Technology Skills teach students to access all aspects of school life by employing various high- and low-tech devices such as a computer with a screen-reading or enlargement program, a CCTV (a video magnification device that enlarges materials on a televi-

sion-type screen), a scanner, a magnifier, or a monocular (a hand-held distance-viewing device similar to a telescope).

8 Visual Efficiency Skills provide training in areas of visual motor (e.g., printing, cutting and pasting), visual discrimination (e.g., identifying the differences between letters, colours and shapes), visual tracing (e.g., visually following a static item such as a line of text),

and visual tracking (following a moving object with one's eyes).

9 Self-Determination Skills focus on problem-solving, self-advocacy, and taking initiative and responsibility for oneself.

The acquisition of these nine ECC skills takes many years. The ultimate goal is for the child to become independent within the school setting. Depending upon his or her needs, the level and intensity of instruction in each area either increases or decreases over time.

There is no set rule regarding which skills are taught at which age; it is an ongoing process that is led by the needs of the child.

Typically, the Teacher of Students who are Visually Impaired will focus on compensatory skills (#1), visual efficiency skills (#8), and social skills (#3) during the kindergarten and elementary years. In middle school and high school, a greater emphasis might be placed on the use of assistive technology (#7), independent living skills (#4), and self-determination skills (#9). However, there is no set rule regarding which skills are taught at which age; it is an ongoing process that is led by the needs of the child.

The inclusion of assistive technology in Canadian classrooms has resulted in almost immediate access to the curriculum for students with visual impairments. Children no longer have to wait for the classroom teacher to enlarge a handout or

¹ Hatlen, P. (1996). The core curriculum for blind and visually impaired students, including those with additional disabilities. RE:view, 28, 25 – 32.



Literacy Centre for Children with Autism

OpenMind Alliance Inc.
160 East Beaver Creek Drive
Unit 21, Richmond Hill, ON., L4B 3L4
Tel: (905) 918-3852
www.OpenMindAlliance.ca
email: info@openmindalliance.ca

enhance the contrast of the worksheet on a photocopier — a CCTV can do the same thing immediately. Students with low vision can access the internet and school internal

learning to identify letters and words on desktop computers in their classrooms rather than using poor quality, teacher-produced worksheets that tend to be difficult to see.

to-class throughout the day. As technology advances, so too do the possibilities for equitable access to all areas of the school curriculum.

With the guidance of a qualified Teacher of Students who are Visually Impaired, children with low vision can be successful in school and in life. The ECC serves as a comprehensive framework within which these skills can be achieved both at school and at home. ■



networks as efficiently as their peers with sight. Although the traditional CCTV takes up as much space as a desktop computer, there are now portable devices that can fit in a backpack. Four-year-old children are

Scanners and large screen laptop computers with screen enlargement and speech output capabilities make note-taking and paper-writing easier and faster for older students with low vision as they rotate from class-

Dr. Carol Farrenkopf is the Coordinator of the Vision Program for the Toronto District School Board. She is also an Associate Editor for the *Journal of Visual Impairment & Blindness* and an Assistant Professor-Limited Duties with the University of Western Ontario. She has over 20 years experience educating children with visual impairments.

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

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- Did you know that setting up a discretionary trust can prevent a negative impact on your exceptional child's social benefits as a result of an inheritance?

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

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imprints

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

April 7, 2009, is a day Terry Boyd will long remember.

It was on that day that she was awarded the Governor General's Caring Community Award by the Right Honourable Michaëlle Jean, Canada's Governor General, at Rideau Hall. A self-described "farmer's wife" from South Mountain, Ontario, Terry has sat on the board of the Ontario Rett Syndrome* Association for over 19 years, served for seven years as the Canada-wide manager of the Canadian Resource Centre for Rett, and assisted with the development of Canada's one-of-a-kind Rett Syndrome clinic at the Children's Hospital of Eastern Ontario.

I wanted to give hope, like the hope I had been given.

It was the diagnosis of Rett Syndrome of one of Terry's three children at 23 months, which initiated Terry and her husband to the condition and served as the motivation behind Terry's activities. "I broke down, and Dean, my strong husband, shed his first tear. We wanted hope and purpose," said Terry. "Thank goodness, both came into our life."

They met Molly Bruce, an exceptional parent whose son has autism. "Molly gave me the best piece of advice I could have been given: get knowledgeable. This is exactly what I did and continue to do. Knowledge has helped me give Kayleigh the best quality of life and gave me hope."

For over two decades, Terry has shared her expertise in the field of Rett Syndrome with other families touched by the disorder in search of support and education. ■



Terry Boyd

*Know a person or organization
worthy of national recognition?
Send your nomination to
imprints@exceptionalfamily.ca*

* Rett Syndrome is a genetic disorder marked by progressive deterioration, seizures and cognitive impairment that principally affects females. For more information on Rett Syndrome, visit www.rett.ca



Sure I can

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

Roll a Mile in our Chairs



PHOTO: JULIAN HABER

Kevin Harrison knows the challenge of getting around in a wheelchair first hand. The 34-year-old National Director of Corporate Giving for Muscular Dystrophy Canada was born with muscular dystrophy (MD) and has used a wheelchair for mobility since he was 16. MD is a genetic disorder that progressively weakens the body's muscles to the point where they may stop functioning. In Kevin's case, the condition affects his hands and feet. It was the diagnosis which inspired Kevin to pursue a career dedicated to raising funds for others with special needs.

Prior to joining Muscular Dystrophy Canada in 2009, Kevin served as the Executive Director of Montreal's Action Centre, a bilingual activity center for adults with physical and/or cognitive disabilities. It was there, in 2005, that Kevin and Jamie Orchard, senior anchor at Global Quebec, came up with an idea for a fundraiser aimed at generating awareness about the experience of having to rely on a wheelchair for mobility. "We thought it would be nice to raise money for the Action Centre, and [initially] brainstormed about holding a wheelchair basketball challenge," recalled Kevin. Instead of a sports event, one idea led to another and the "Chair Aware Challenge" was born. The challenge invites interested Canadians to raise significant funds (participation fee for Montrealers, Torontonians and Calgarians is \$2,000, while Ottawans must amass \$1,000) and receive a manual wheelchair in return, which they are encouraged to spend a day in – a difficult feat for people accustomed to moving around independently.

Following the Action Centre's first Chair Aware Challenge in 2006, the center made it an annual event. In 2008, Kevin brought the concept to Muscular Dystrophy Canada in Ottawa, where it will now be held yearly as well. "The response has been steady," noted Kevin, adding that Toronto's inaugural fundraiser in May

attracted roughly 50 participants. Fifteen signed up in Ottawa this year, and between 20 and 25 people joined in Montreal. "Our goal is that participants will have a newfound respect for the disabled community."

One such participant who has gained appreciation for the obstacles faced by people with physical disabilities is Montreal burlesque dancer and performer Holly Gauthier Frankel. Holly's father, Ronny, suffered a brain aneurysm in 2004 which left him with impairments comparable to those brought on by a stroke. Having lost his ability to walk, he used a wheelchair for several months until he eventually regained limited mobility. In 2006, Ronny began to attend the Action Centre in search of support, companionship and stimulation – a decision Holly credits with having "saved" him. "The center has given [my father] something to do and gives him people to talk to," explained Holly. Grateful for the organization's help, she was determined to reciprocate the kindness. She began to volunteer there and in 2007, performed a cabaret show at the centre's Halloween party.

Eager to help

When Kevin approached Holly to try the Chair Aware Challenge in the center's honour, she immediately agreed. "I thought it was important to do given how much I use my arms and legs in dance. What would it be like to be in a wheelchair if I could not use them?" Holly mused. "I did not want to take [my mobility] for granted and I wanted to give back to the center."

Holly was met with mixed reactions when she shared her plans with friends. "Most people would not dream of spending a day in a wheelchair if they did not have to. Most were impressed that I was willing to do it. I was met with a lot of support, some shock as well."

While some Challenge participants choose to limit their wheelchair-time to a few hours or simply use it around



their office, Holly was determined to use hers to experience a full day. “I had all these goals about moving around and getting around the city, but once I physically got into the chair, I realized they were not possible. It took me all day to get to the coffee shop, to the mall and home, and I still needed help from a friend for most of the day after realizing how hard it was to wheel myself around. I ended up getting out of the chair a fair amount because otherwise it was impossible to manoeuvre,” she recalled. Tasks which Holly assumed would be simple, such as wheeling along a sidewalk or taking the bus, proved to be extremely onerous.

“At the end of the day I had a mixture of feelings; I felt triumphant, exhausted – emotionally and physically – and infuriated, because it just kept on dawning on me that life in a wheelchair is not easy. Every crack and crevice in the sidewalk attested to how hard it is to be in a wheelchair. When I was in the chair, everything I thought I knew went out the window and I had to pay attention to everything that was happening.”

We all know the expression “Never judge a man until you’ve walked a mile in his shoes.” Perhaps if more people would follow Holly’s example and roll a mile in our chairs, there would be a greater understanding and integration of people with disabilities. ■

To learn more about the Chair Aware Challenge, visit: www.centreaction.org/ChairAwareChallenge.htm or www.muscle.ca/national/home.html

Michael Lifshitz, CA, MBA, is a consultant for Investors Group Financial Services Inc. in Montreal. Contact Michael at sureican@exceptionalfamily.ca

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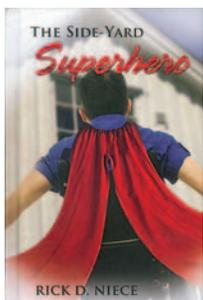


& Classics

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

The Side-Yard Superhero

By Rick D. Niece
Synergy Books, 2009
175 pages, \$21.07



The *Side-Yard Superhero* is perhaps best summarized in a word: “sadappy”, a term akin to bittersweet, coined by author Rick Niece to describe the simultaneous feeling of joy and sorrow. In his compelling autobiography, Niece recounts his childhood as a paper-boy in small-town DeGraff, Ohio, and the friendship he cultivated with an exceptional boy named Bernie Jones. With passion, candour and humour, Niece paints a picture of two youngsters whose lives are characterized by stark contrasts: one young, healthy, educated and self-sufficient, the other older, with cerebral palsy, housebound, confined and totally dependent. And yet, a common love of Dick Tracy, carnivals and adventure binds the two in a relationship that defies all boundaries – a rapport that has less to do with reciprocity and more with Niece’s overwhelmingly giving and kindhearted soul. Sadappy parts emerge throughout, particularly in Niece’s depictions of the highs and lows of Bernie’s life; which, although marked by tremendous isolation and discomfort, was made significantly brighter and

“We really are different, aren’t we Rickie?” He looked so sad...

“We aren’t that different, Bernie. You and I aren’t that different. We really aren’t.”

*My words sounded hollow.
We were different, and
the reflections of truth
staring back at us did not lie
no matter how hard I tried to.*

- *The Side-Yard Superhero*

more meaningful by regular visits from his best (and seemingly only) friend, “Rickie”. The beauty lies not in Niece’s recollections of all that he gave to Bernie, but of all that Bernie gave to him by way of his exemplary courage and acceptance of his disability.

Niece’s insertion of moving poetry throughout the book makes up for his inclusion of certain incidents and characters that readers exclusively interested in Bernie Jones may find superfluous and irrelevant. Of note, conversely, is a chapter highlighting Niece’s experiences at a local carnival in an era where freak shows were commonplace; for it contextualizes the community’s neglect of Bernie “the cripple”.

The fact that Niece categorizes his work as a “mythography” suggests that some parts of the narrative are embellished; but like Sasha Baron Cohen’s films, it’s hard to tell which components are real and which are disingenuous. Ultimately any truth-stretching becomes inconsequential, however, since the package as a whole and its messages within are quite authentic. *The Side-Yard Superhero* is painful and heart-breaking; it is also eloquent and heartwarming, and offers lessons

www.autismawareness.ca



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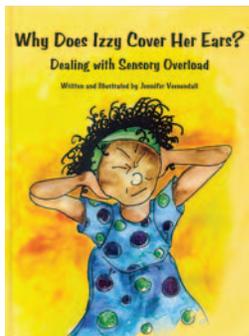
A portion of all our sales is donated to an autism-related charity.
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that, decades after the events occurred and long after Bernie's passing, never grow old. ■

Why Does Izzy Cover Her Ears? Dealing with Sensory Overload

By Jennifer Veenendall
Autism Asperger Publishing Co.,
2009, 39 pages, US \$18.95



by LAUREN SILVER

Geared for children ages 6 to 9, *Why Does Izzy Cover Her Ears?* recounts the story of Izzy, a fictional first-grader with a very real condition: Sensory Processing Disorder (SPD). Among other characteristics, SPD is marked by difficulties in processing sensory information transmitted via the five senses. For Izzy, the disorder contributes to her particular discomfort in noisy environments as well as those in which she is inadvertently touched by others – something that occurs almost daily when Izzy tries to access her locker amid throngs of fellow students.

Elaborate classroom decorations also distract Izzy, who has trouble focusing. Fortunately, her teacher and occupational therapist are very accommodating and present her with solutions to surmount some of her challenges. Izzy's locker is switched to the end of a row to afford her more space, she is given earplugs to use as needed, and her teacher removes many classroom decorations and adjusts the lighting in order to make Izzy feel more at ease.

*Grace could draw trees
that don't look like lollipops.
Her trees look like real trees.
And she can make a rhyme
with any word you say.
But she has a voice
that hurts my ears.
It makes my insides rattle.*

- *Why Does Izzy Cover Her Ears?*

Izzy also employs a number of relaxation techniques that contribute to her sense of empowerment over her disorder; she talks about the comfort of a weighted blanket, a squishy fidget toy that helps her to calm herself, and a "motor room" where she releases pent-up feelings and energy. While she previously

had to restrain herself from exhibiting violence toward others whose behaviours upset her, the book ends on a high note with Izzy being in control of her emotions, happy, and confident in her new class.

Written by an OT, *Why Does Izzy Cover Her Ears?* sensitizes children to the common reactions of youngsters coping with sensory overload; reactions – including crying, tantrums and cowering under a desk, for example – that, if left unexplained, might be perceived as strange and/or juvenile by observers. Kids will relate to Izzy, who attends a mainstream school and narrates the story in typical 6-year-old fashion, qualifying that she "started first grade 32 days ago." Izzy employs a couple of expressions, however, that are beyond most first-graders' vocabulary: references to "line basics" and "morning meeting", reflect the author's attempt to target educators and children alike; an effort that falls flat and detracts from the book's child-friendly appeal.

Ironically, although vivid illustrations complement simple sentences, certain pages are filled with inordinate amounts of text and the font is dizzying to read – something that might irritate children (and those with SPD in particular) who may wish to tackle the book independently. Izzy's mention that she "threw tantrums to get out of class", may also be misconstrued as a reward by some readers, who learn that Izzy's poor conduct perpetually yields a chance to visit the principal and sit on his beanbag chair – which she "loves".

Veenendall's inclusion at the back of the book of stimulating discussion questions and useful resources for teachers, parents, and children, may compensate for parts of the book that fall short. ■

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Sharing our Stories, Seeking Support

Courageous parents speak candidly
about the challenges and triumphs
of raising their special children



Marie Josée and Alrica



David



Owen and Ethan

by DONALD BIDD

As the father of a wonderful 22-year-old man who has a significant cognitive disability (resulting from a brain disease called tuberous sclerosis), I have always found the testimonials of fellow exceptional parents particularly moving. Throughout my own difficult times and struggle to accept that my son Justin will have a lifelong disability, my heart has often been strengthened and nourished by others' stories of trial and success. In fact, it was the very faith and encouragement of others which literally helped me to survive.

I often think that the real sadness is not the disability of a child, however shattering this reality is; but rather, it is living this reality alone. In the conviction that it is both healing and useful for us to share our feelings and experiences, I presented several courageous moms and dads with a set of questions and invited them to reflect upon their unique emotions and experiences. I hope their answers will touch and inspire you, perhaps to reach out to someone else. But at the very least, I hope they underscore the fact that you are not alone.

Thérèse Bélanger-Ardron of Dorval, Québec, is a single mother of two energetic teens who have Down syndrome; Marie Josée, 16, who was adopted at a month old, and Alrica, 13, a foster child since age two. Marie Josée and Alrica love music and dance, are “amazing” equestrians and swimmers and just recently discovered the joy of cheerleading.

Amy Dawson of Toronto, Ontario, is the mother of David, 24, an only child with multiple disabilities, including cerebral palsy, a seizure disorder, mild developmental delay, and occasional behaviour challenges. An avid musician and DJ, David is deeply connected to his community and sings in a young-adult choir. His winter “obsession” is electric wheelchair hockey, and his summer passion is sailing and “anything water-related.”

Leah and Rob Lance of Kincardine, Ontario, are the parents of Ethan, 6, and Owen, 3, both of whom are on the autism spectrum. A happy, loving boy, Ethan adores Thomas the Tank Engine and dinosaurs. Ethan was diagnosed with severe early infantile autism with serious impairment in cognition, communication, gross- and fine-motor skills. He also exhibits signs of pica¹ and echolalia². Owen is an affectionate child who loves cars and pretending to cook. He was diagnosed with early infantile autism on the milder side and also exhibits echolalia.

1 Pica is an eating disorder characterized by a craving for non-nutritive substances that persists beyond a period of a month, at a time when it is considered inappropriate for a person's developmental stage. Some of the substances people with pica may eat include paper, wood, flour, sand, clay, glue, chalk, chewing gum and laundry detergent.

2 Echolalia is the immediate or delayed parrot-like repetition of a word or phrase made by another person. It may manifest in various syndromes including autism, Tourette's, Rubinstein-Taybi syndrome, as well as in children with visual impairments.



What is the greatest challenge you have faced in the care of/or in your relationship with your exceptional child?

Thérèse: The greatest challenge is no doubt the enormous responsibility of teaching, advocating for and raising two children with special needs as a single, full-time working parent! Seeing so much potential [in my girls] and not having enough time to fully teach and encourage them can be quite overwhelming.

Amy: The greatest challenge I faced was not knowing what the future held for my child after his initial diagnosis and throughout his childhood. I wondered whether he would remain at the same place of development. The other challenge was and continues to be the endless repetition of the same methods to correct behaviour and redirect inappropriate language, and feeling I've done something 20 000 times before and it's had no impact. Sometimes I thought my attempts were essentially futile as I didn't know whether David would ever learn. Of course ultimately none of it was futile, as David progressed at his own pace. He continues to evolve, grow and expand in his potential.

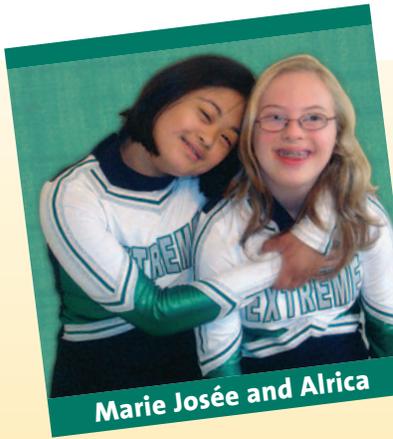
Leah & Rob: The greatest challenge we faced was coming to terms with the fact that our boys are on the autism spectrum and thinking about the future; for example, once we pass on, what will happen to our boys? How will we cover all the costs for any future therapies or supported housing? On a daily basis, everything seems to take longer to do with children on the spectrum. If we want to go somewhere, it is almost as though we have a baby again. We have to pack a diaper bag "just in case", in preparation for meltdowns, toileting accidents and sensory issues. Another challenge is the public's perception of our children or us as parents; if our child is overwhelmed and has decided to lay down on the ground and scream, it is not because he is spoiled; he may be reacting to the fact that he finds the environment too noisy or over-stimulating.

What, if anything, was most difficult to accept around your child's diagnosis?

Thérèse: In this respect, our situation is unique; it was actually *because* of my daughters' disabilities that we became a family. *Choosing*

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Marie Josée and Alrica



David



Owen and Ethan

exceptional children automatically changes the emotional dynamics within the family unit. However, what was attached to Marie Josée's disability – namely a cardiac condition and respiratory challenges – certainly brought periods of intense

and hours later crash into a pit of despair. I began to measure my life by how long I stayed in the pit. Usually within a few hours, or a couple of days at most, I could pull myself out. But there were periods when I was so despondent, when it

Leah: I remember one day in my kitchen, screaming at my husband about how unfair it is that our son will never have a best friend, a wife, children, a job. It was just after Ethan's diagnosis became official, and it had really hit me. I decided then that we were going to prove the doctor wrong about the things he said Ethan would never learn.

I remember screaming at my husband about how unfair it is that our son will never have a best friend, a wife, children, a job.

Do you recall a particularly joyful memory (a breakthrough, a moment of pride) in your experience with your exceptional child?

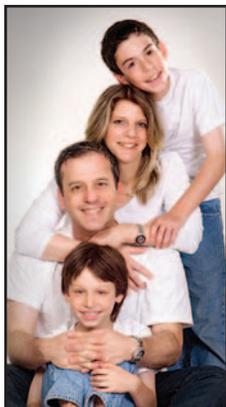
fear and anxiety. At six months Marie Josée underwent heart surgery and later needed a pacemaker; these events certainly made me realize how fragile and precious life is!

seemed there was no way back to the light, and I just wanted to end it all. However, ending it all for myself would have meant leaving my son behind... I thought briefly about taking him with me. But since I knew I could never truly harm him or leave him, the only option was to carry on and believe that in time, light would emerge from the darkness.

Thérèse: It is so difficult to choose one event or moment; there are so many! Having a child with a disability makes you so aware of all the tiny miracles a typically-developing child lives through each and every day! With Marie Josée and Alrica, I had so many questions and concerns about their development and there were so many moments when they rose above my expectations; from their first words and first steps, to their class presentations and recent participation at a provincial cheerleading competition (neither I nor doctors knew with certainty whether they would ever speak or walk). I have shed many tears of joy and pride and expect many more!

Amy: Having a child with a disability is like continually riding an emotional roller-coaster. You can wake up one day with boundless optimism

Amy: There are so many joyful and triumphant moments, but I think what resonates most strongly with



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me to this day is the development of my son's vocabulary. Adding a new expression or new word to his vocabulary and using it in the correct context would bring me untold joy. When David was about eight years old, he told me he saw his reflection in the mirror. That was the first time he used the word "reflection" and it felt like he had achieved perfection!

Leah & Rob: Do we have to pick just *one*?! A breakthrough for us was when Ethan asked to go to the bathroom on his own, for the first time ever! He just said, "Poop in toilet?" He was five years old, and we were told that this would *never* happen.

Describe the impact that having a child with a disability has had on you and your family.

Thérèse: *What we do, how we do it, where we go and why we go are all influenced greatly by the girls' abilities, strengths, needs and interests, and of course, my energy level! As a family unit however, unfortunately we are often perceived by others as "special" or "different" and that perception itself seems to create a barrier that separates and isolates us from other families. Who we are and the way we live as a family may not be perceived as "typical", but neither is the abundant joy and connectedness we share!*

Amy: Having a child with a disability has touched and shaped every aspect of my life. From the house I live in, to the car I drive and the jobs I've held, my son's disability is central to everything. It has fashioned how I look at locations (wherever I go, I always evaluate whether the space is wheelchair-accessible for David), people and the

world. His constant care demands made it difficult over the years to sustain other meaningful relationships beyond our nuclear family, and as a result there are not a lot of people in our lives.

Leah: My brother has a terminal heart disease, so I was always the "other" child, while my parents dealt with my brother's health issues. My experience has made me more aware of my younger son's needs for equal attention. Having two exceptional children has been trying on our marriage at times. People always ask me how I "do it". I just do. I don't know any other way to be a parent.

How do you reach out for support for the challenges you face? Do you find it easy or difficult to open up to others and share what you are living?

Thérèse: Not an easy question to answer! When the children were younger people seemed to have been more involved/connected to us. Over the years there has been a growing isolation and we seem to be more and more on our own. I don't think this has been a conscious choice, but a reality which has slowly filtered in over time due in part to the fact that I find it difficult to continually ask for help. Emotional support in difficult times

comes from a few close friends, but for the most part I try to manage on my own. I must admit that at times it does feel like a lonely journey.

Amy: It is not easy for me to reach out for support, since I am highly self-sufficient and try to depend on others as little as possible. Not having a lot of control over David's disability has made having control in all other aspects of our lives essential. Having said that, though, I have always found an incredibly accepting community of people in my former work environments. From the time he was very young, David would visit my place of work. He was always welcomed and made an impact by greeting everyone and getting to know them.

Leah & Rob: We have a great support system of friends who are there for us no matter what. We have a few friends who are teachers and daycare providers, and they often share their knowledge of other support channels we might be able to pursue to help make our journey a little easier. We also couldn't do it without the help of Leah's mom. We share whatever we can with other parents of exceptional children. If we can give another parent a tip that opens their window up a little more, why not? We would hope that people would do the same for us. ■

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In

Focus

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

The Amazing Brain

Neuroplasticity or brain plasticity refers to the ability of the brain to reorganize itself in order to learn something new or to compensate for a brain function that has been lost.



PHOTO: JULIAN HABER

In recent years, scientific studies have increasingly emphasized the role of mental stimulation in maintaining and even improving healthy brain function. While everyone can benefit from brain stimulation, the latest discoveries are particularly relevant to parents seeking to strengthen weaknesses in their children diagnosed with cognitive impairments. Of course as your child's primary caregiver, it is equally important that you maintain healthy brain function, especially in light of the fact that your mind is constantly active in researching, storing and applying important information related to your exceptional son or daughter. This instalment of *In Focus* will highlight a number of easy brain-training exercises you can do, or adapt for your children.

But first, a little history: In our grandparents' era, it was believed that the brain was pretty much genetically hardwired at birth. Only something as significant as a stroke or other brain injury could alter our predestined intelligence and the sole possible change was expected to be both negative and irreversible.

By our parents' time, it was concluded that the brain actually took several *years* to develop fully. Those years were thought to represent a narrow window of opportunity in which children's brains could be stimulated and their intelligence potential drawn out.

Then in our generation, an amazing thing happened. Stories from the neuroscientific world began to emerge of adult brain-injury victims who had relearned to speak or walk or write, even though the parts of their brains responsible for those functions had been severely damaged – sometimes even completely destroyed.



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The following simple brain exercises can be adapted to almost any age and/or cognitive level to strengthen specific areas of cognitive weakness.

Memory:

- Play a “matching pairs” or concentration-type game
- Draw a route map from memory (e.g. from your home to work)
- Think of countries that start with a certain letter
- Memorize a new poem or song
- List the contents of your purse or briefcase, without looking

Visual-Spatial and/or Fine Motor Skills:

- Do jigsaw puzzles and mazes
- Construct something out of origami
- Use a mirror to print your name on a paper so that it's legible in the reflection

Attention:

- Break routines (e.g. use your non-dominant hand or close your eyes when performing a routine task)
- Play bingo, or Simon Says
- Instruct someone on the performance of a task while your back is turned. The task may be as simple as making a sandwich, or drawing a geometric pattern. Have the other person follow your instructions to the letter, even if you leave out important details
- Play “spot the difference” or “find what's missing” games found in books, newspapers, or online

Executive Function:

- Draw several circles on a page, write the name of a different colour in each one, then colour them in with a different colour. Then say the colour of the circles (not the written word) aloud, as fast as you can
- Recite the alphabet aloud, alternating with numbers (A-1-B-2-C-3 etc.)
- Plan a vacation or theme party in detail, even if it's just an imaginary one
- Compile a grocery list for the week, listing each item aisle by aisle, from memory.

As the field of neuroscience came into its own and words like “neuroplasticity” were introduced within our collective vocabulary, we began to understand that the brain is capable of changing and improving itself long into adulthood.

Neuroplasticity or brain plasticity refers to the ability of the brain to

reorganize itself in order to learn something new or to compensate for a brain function that has been lost. And it appears that we can kick-start this ability by doing brain exercises, at any age, and at almost any level of cognitive functioning.

Certainly the early years of life constitute the period in which the brain

absorbs information with extraordinary efficiency, and learning is achieved at an accelerated pace. Recovery is also most rapid in these years, and so for children with special needs, early intervention will always remain key. But we now know that the brain's potential to rewire itself, given the right conditions, has no expiration date. It is never too late to try to improve cognitive function.



How neuroplasticity works

Information is processed in the brain via neurons. Every action or thought requires countless neurons to fire in different parts of the brain, and to communicate with each other along neural pathways. Every time we learn a new skill, existing or new neurons are stimulated, connect to each other, and form new neural pathways. As Donald Hebb, a famous Canadian neuropsychologist said, “Neurons that fire together, wire together.” And every time we repeat a skill, those neurons and pathways are strengthened.

As with physical exercise, cognitive cross-training is highly recommended. It's not enough to exercise just one set of muscles in order to

achieve total body fitness. Similarly, when it comes to brain training, doing crosswords or Sudoku alone year after year isn't enough to maintain your brain's peak performance level. The development of neurons and new neural pathways is most active when the brain is learning something **new** – whether it's as complex as a new language or ballroom dancing, or as simple as taking a new route to work. Repetition maintains and strengthens the neural pathways that were formed during the learning process, but it's not nearly as potent a brain workout. And neurons and pathways that aren't used eventually erode, in much the same way that muscles atrophy when they aren't exercised. In both cases, it's a question of "use it or lose it."

What you can do

Generally, the rule to remember is that if you can do an activity on "automatic pilot," it's not giving your brain a workout. So instead of a daily crossword, try doing a jigsaw puzzle occasionally. Have fun learning a new skill like playing a musical instrument, or take a class in something you've always been interested

in. Do routine things in new ways – like using your non-dominant hand to open a door with a key, or close your eyes as soon as you get in the door and use the "visual map" in



your head to find the closet, hang up your coat, and navigate through your home. Shop at a new grocery store. Do mental calculations in your head instead of using a calculator. Watch a TV show with the volume off, and see if you can figure out what's happening. Give your memory a workout by trying to

remember every city you've ever visited, or every person you spoke to yesterday. Never miss an opportunity to stimulate your senses. Find something in your tool drawer (or better yet, your "junk" drawer!) by using your sense of touch exclusively. Try to identify the contents of spice jars by smell. Combining senses is even more effective. Smell flowers or enjoy a meal while listening to music, for example. There are countless opportunities in an ordinary day to challenge your brain and keep those neurons firing. This is true for everyone of any age, from people who are cognitively gifted to individuals with impairments.

Nature and nurture

Neuroplasticity does not detract from the role that genes play in defining individual potential. We are all influenced by our genes as well as our environment. Factors like nutrition, physical exercise and stress management significantly impact brain fitness too. Fortunately, these are all factors we can control, just as we can choose to incorporate brain exercises into our daily routines. Until some future generation comes up with a magic "brain pill" or high-tech neuron regeneration implants, keeping our brains fit should rank just as high on our priority lists as keeping our bodies in shape. ■

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

Just Take a Bite!

More

Easy, Effective Answers to Food Aversions and Eating Challenges

The fourth article in our unique Food For Thought series

by LORI ERNSPERGER, Ph.D

In the last issue of Exceptional Family, we explored the characteristics of resistant eaters and highlighted the elements of a successful treatment plan designed to solve your mealtime challenges. Whereas the first part of the plan revolved around **Environmental Controls**, the second part focuses on your child's **Physical and Oral-Motor Development**.

The source of some eaters' resistance may stem from minimal to severe delays in oral-motor development or a lack of appropriate physical supports to promote their successful participation at mealtimes. The next part of the treatment plan will therefore address the physical and oral-motor skills necessary for eating.



Guidelines for Improved Oral-Motor Development

A Explore various techniques and tools designed to ameliorate oral-motor functioning. Some interventions use facial massage or stretching of the muscle fibers of the cheeks and lips, while others incorporate the use of items such as whistles and straws to improve oral-motor skills. Remember, it is up to the child to give permission for the adult to enter his or her mouth.

B Increase muscle tone in the jaw, lips, tongue and cheeks.

Oral-motor activities designed to improve muscle tone can be easily implemented in a child's daily routine. While your daughter brushes her teeth, for example, encourage her to move her tongue from one side to the other. Or during the drive to school, sing silly songs that focus on facial actions together. Internationally-recognized speech therapist, Dr. Suzanne Evans Morris' "Marvelous Mouth Music" CD, offers child-friendly songs which focus on oral-motor development.

C Kids with oral-motor difficulties often resist foods that require extended chewing because they find the process too physically-challenging. The act of chewing constitutes a partnership between the tongue, the jaw and the cheeks. Parents can create a "chew box" of age-appropriate chewing materials designed to build jaw strength and increase movement of the tongue, lips and cheeks.

The final part of the comprehensive treatment plan focuses on the **Stages**

of Sensory Development for Eating.

Children naturally learn to eat new foods through the developmental sensory stages of tolerance, touch, smell, taste, and finally, eating. Toddlers often play with and experience foods while sitting in their high chairs. As toddlers begin to touch and smell new foods they eventually begin to place small amounts in their mouths. These same developmental stages can also be applied to resistant eaters.

Guidelines for Addressing the Stages of Sensory Development

1 Select and implement a few games and daily activities that address each stage of sensory development: tolerance, touch, smell, taste and eating. Begin the program by allowing a new food to be in the vicinity of the child. Tolerance begins with looking at a new food and allowing the food to be present at a meal. It is important for the child to be reminded that he or she will not be forced to touch or eat the new food. After several days or weeks of focusing on tolerance, assist the child to explore new foods through touch. Games like “Hot Potato” (sidebar) can be fun while helping to decrease any anxiety your child may be feeling around handling a new food.

2 Provide opportunities throughout the day outside of mealtime for your child to learn about new foods. Be creative and provide a **food-rich environment**; an environment where the child feels safe to learn about new foods across a variety of settings. Expose your child to plastic foods at bath time, sing about foods in the car, and read about foods at bedtime. Activities and games should run no longer than 10-15 minutes at a time.



Hot Potato:

Exploring new foods through touch

You will need:

- 4 new foods
- 4 preferred foods
- Music
- Small group of children or family

Procedures:

- 1** Depending on the child's comfort level around handling the food items, they may be held directly or placed in an open bowl or plastic bag.
- 2** Sit in a circle. Turn on the music and begin to pass one food around the circle, just like in the typical version of “Hot Potato”. Turn off the music.
- 3** The person holding the food when the music stops must make a statement about the item, for example: “The carrot is orange” or “The lemon is round.” Or, have the person smell or taste the food, based on his or her comfort level.
- 4** The same person is now in charge of selecting the next food to pass around.
- 5** The game is finished once everyone has had an opportunity to select a food.

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3 Have fun and avoid coercion. The goal of each lesson is for the child to lead the activities and enjoy learning about new foods. Strong and enthusiastic role models will reduce the child's degree of neophobia and foster his willingness to learn. When interacting with younger children, you may wish to use a puppet as a role model, which is sure to capture their attention.

4 Enlist typical peers' or siblings' support. At home, invite one or two typical peers over to participate in the activities. At school, typical peers may also be invited to play food-related games and model positive eating habits. Be sure to select children who will be encouraging and compliant during the session.

5 It is perfectly alright to repeat the same sensory activity several times. Children learn through repetition and enjoy playing games they are familiar with. Acquiring a taste for new foods may take several weeks or even months. It may take up to 10 to 15 exposures to a new food before a resistant eater is ready to move on to the next sensory stage

of development. Therefore, a comprehensive treatment plan should include multiple opportunities for exposure at each sensory level.

6 Just as adults have food preferences and dislikes, not all children like the same foods. In order to be considered a "good eater," a child doesn't have



to like every food. A good eater is one who enjoys eating, likes a variety of foods from each food group, and can tolerate new foods. If a child truly does not like a food after 10 attempts at exposure, select another food from the same food group.

When teaching your child about new foods, a positive relationship is critical between your child and those working with him or her.

Accordingly, people involved in implementing the treatment plan should have adequate knowledge and skills for addressing the issues of resistant eaters. A collaborative approach within a multidisciplinary team will ensure the long-term success of the program.

Lastly, I cannot emphasize enough the importance of maintaining a well-balanced perspective when managing a child's eating challenges. Although at times this may be extremely difficult to do, parents must consider the long-term goals for their child and family while minimizing the focus on day-to-day struggles that each mealtime may bring. Children have an innate ability to learn new things at their own pace. As parents and professionals, we must respect their limitations and celebrate their successes. Happy eating! ■

Dr. Lori Ernsperger is from Henderson, NV, where she is the owner of Autism and Behavioral Consulting. She received her doctorate in Special Education from Indiana University and has over 23 years of experience working as a classroom teacher, administrator, and behavioral consultant. Dr. Ernsperger currently provides staff development and conference workshops on a variety of topics to school district personnel and parents. She is the author of *Keys to Success for Teaching Students with Autism* and *Just Take a Bite: Easy Effective Answers to Food Aversions and Eating Challenges*. Her new book, *Girls Under the Umbrella of Autism Spectrum Disorders*, is published by Autism Asperger Publishing Company. Contact Dr. Ernsperger at (702) 616-8717 or drlori@cox.net.

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Insights

A compilation of upcoming conferences and training sessions of interest

September 14

Discover the Answer to Dyslexia Dyslexiability

Featuring best-selling author and learning difficulties expert, Ronald D. Davis. Explore how people with learning difficulties think, how difficulties develop, and how to correct the condition. No admission fee, but donations to Dyslexiability welcome online or at the door. 6 pm. Harold Greenspon Auditorium, Côte Saint-Luc City Hall, 5801 Cavendish Blvd, C.S.L, QC. Info: (514) 815-7827, info@dyslexiability.com or www.dyslexiamontreal.com

September 15-18

Positive Practices in Behavioural Supports through Non-Linear Applied Behaviour Analysis

Kings Regional

Rehabilitation Centre

Conducted by Jo Mullins of California's Institute for Applied Behaviour Analysis. Full Series (Seminars 1 – 4): US \$600/ Daily Rate: US \$175. 9 am - 4 pm. 300 Commercial Street, Berwick, NS. Info: (902) 538-3103 x168, jroop@krcc.ns.ca or www.krcc.ns.ca

September 16 / October 21

Walk a Mile in My Shoes

Integra

This experiential workshop is designed to increase knowledge and understanding about how it may feel to have learning disabilities. \$10. September 16: 7 pm - 8:30 pm. October 21: 9:30 am - 11:30 am. 25 Imperial Street, 1st Floor, Toronto, ON. Info: (416) 486-8055 or www.integra.on.ca

September 30

Anxiety & Learning Disabilities

Integra

In this introductory workshop, participants will gain an understanding of the relationship between anxiety and learning disabilities, different types of anxiety and treatment approaches. \$10. 7 pm - 8:30 pm. 25 Imperial Street, 1st Floor, Toronto, ON. Info: (416) 486-8055, info@integra.on.ca or www.integra.on.ca

October 7

Adaptive Technology

Integra
Make connections between a child's learning needs and types of assistive devices and programs. Learn how to encourage children to use these accommodations, and when they may not be useful. 25 Imperial Street, 1st Floor, Toronto, ON. Info: (416) 486-8055, info@integra.on.ca or www.integra.on.ca

October 23

4th Annual Tools for Life Conference & Exhibit 2009

Featuring exhibits and educational sessions from over 100 presenters dedicated to overcoming barriers and making living, learning and working easier for youth, adults and seniors with disabilities. Free. 9 am - 3:30 pm. Horton High School, 75 Greenwich Road South, Wolfville, NS. Info: (902)538-1190, info@tools4life.ca or www.tools4life.ca.

November 4

Bullying & Learning Disabilities

Integra

Explore bullying (both face-to-face and online) as it relates to children with LDs. Prevention and intervention strategies will be covered briefly. \$10. 7 pm - 8:30 pm. 25 Imperial Street, 1st Floor, Toronto, ON. Info: (416) 486-8055, info@integra.on.ca or www.integra.on.ca

November 5-6

Symposium 2009 Abe Gold Learning and Research Centre

The symposium will address the challenges of healthy development in people with developmental disabilities. Featuring keynote speakers Drs. Robert Joseph, Lee Marcus, Dermot Bowler and Robert Hodapp. Professionals: \$190/day, Parents/ students/people with ASD: \$90/day. 8:30 am - 4:30 pm. 3500 du Souvenir, Laval, QC. Info: (514)345-8330 x319, info@goldlearningcentre.com or www.goldlearningcentre.com

November 6

Maximizing Auditory Potential in Children with Hearing Loss who have Additional Challenges

VOICE for Hearing Impaired Children

Learn how to develop effective auditory, speech and language programs for children with hearing loss who have complex needs. \$175. 9am - 4pm. Horseshoe Valley, Barrie, ON. Info: (416)487-7719, info@voicefordeafkids.com or www.voicefordeafkids.com

November 11

Executive Functioning & Learning Disabilities

Integra
Explore the nature of executive functioning, and the challenges children with LDs may experience in self-regulation. Learn tips to support kids with executive function difficulties. \$10. 7 pm - 8:30 pm. 25 Imperial Street, 1st Floor, Toronto ON. Info: (416) 486-8055, info@integra.on.ca or www.integra.on.ca

November 18

Language-Based Learning Disabilities

Integra

Gain an understanding of how language processing difficulties may present in academic and social contexts. Learn tips to support kids with language-based LDs. \$10. 7 pm - 8:30 pm. 25 Imperial Street, 1st Floor, Toronto ON. Info: (416) 486-8055, info@integra.on.ca or www.integra.on.ca

November 23-27

TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children)

Abe Gold Learning and Research Centre

Conducted in French, this course provides basic training on Structured and Individualized Intervention in its application to autism, PDD and other disabilities following the prescriptions of the TEACCH model and of Dr. Eric Schopler of the University of North Carolina. Professionals: \$1290, Parents/students/persons with ASD: \$650. 9 am - 5 pm. Miriam Foundation, 8160 Royden, T.M.R. QC. Info: (514) 345-8330 x319, info@goldlearningcentre.com or www.goldlearningcentre.com

Ongoing

Training Opportunities

Geneva Centre for Autism

Year-round training sessions on ABA, Social Skills, Sexuality, Asperger syndrome, Education and more! 112 Merton Street, Toronto, ON. Info: (416) 322-7877 x235, traininginstitute@autism.net or www.autism.net

Ongoing

Professional Development

Lester B. Pearson School Board Centre of Excellence for Autism

Year-round professional development opportunities with our Lecture Series and annual Symposium. Info: www.lbpsb.qc.ca/eng/asdn/index.asp and click on "Resources" tab.

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