

# Exceptional

Vol. 4 No. 4 • Summer 2009

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MAGAZINE FOR PARENTS  
OF EXCEPTIONAL CHILDREN

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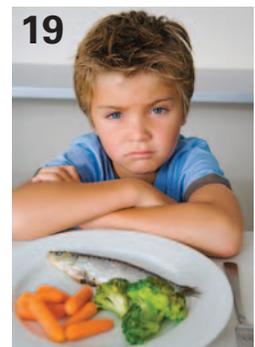
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# Exceptional Family

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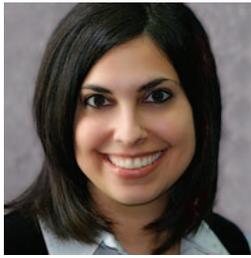
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## FROM THE EDITOR

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PHOTO: JULIAN HABER



### *A Milestone – and Some Miles to Go*

You don't have to be an editor to know that when an event makes headlines, it's either controversial, or unprecedented. The latter accounted for prominent coverage by various Montreal media outlets, of a recent Bar- and Bat-Mitzvah ceremony.

The particular ceremony that captured the attention of the CBC, CTV and Montreal's English-language daily, *The Gazette*, was no ordinary celebration. Sponsored by the Miriam Foundation, Miriam Home and Services and a local synagogue, this event fêted the Bar and Bat-Mitzvahs of six men and women aged 24 to 58 with developmental disabilities – men and women whose spiritual place within the Jewish community has often been overlooked.

In Judaism, the Bar-Mitzvah (or Bat-Mitzvah, for girls) ritual marks the coming-of-age of a boy who turns 13 and a girl who turns 12. It celebrates the point at which a young adult officially becomes responsible for the adherence to Jewish laws, traditions and ethics, and his or her participation in all areas of Jewish community life. It is a serious yet festive occasion that often evokes tears of joy from parents and grandparents grateful to have reached this milestone with their children.

Together with approximately 600 other attendees, I had the privilege of witnessing this momentous occasion; of watching these dignified individuals stand before the congregation, deliver speeches of gratitude, recite blessings, and bask in their glory as they listened to Rabbi Chaim Steinmetz highlight their attributes to everyone present and relay his pride in their affiliation with the Jewish community. Like other Bar- and Bat-Mitzvahs, this event certainly sparked tears of joy – only this time, the tears were not limited to the family members of the honourees, but to everyone present, who responded with thunderous applause and standing ovations.

Beyond the significance of this celebration for these courageous men and women and their families, the ceremony marked a high point for the community at large. The event served as a crucial reminder that exceptional people need to be welcomed to participate in communal rites and rituals – a point Rabbi Steinmetz eloquently emphasized in his sermon when he stated that “just like a family isn't a family when one of the members is excluded, a community is not a community when some of its members are excluded.”

Indeed, for Montreal's Jewish community, a celebration of this type was unprecedented. The fact that it made headlines in mainstream news reports underscores that its occurrence has lessons that have the potential to touch those far beyond the Jewish community and Montreal. An even greater milestone will have been reached when the inclusion of exceptional people within the spiritual fabric of society becomes so commonplace that it is no longer considered such a rarity.

*Aviva Engel*

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# Registered Disability Savings Plan: A future of financial security

If you or someone in your family is eligible for the Disability Tax Credit, there is a new registered savings program that you should know about: the Registered Disability Savings Plan (RDSP).

The RDSP was introduced by the federal government. This unique plan is designed to help Canadians to save and invest for themselves or a disabled family member in a tax-deferred environment.

“The RDSP is a welcome addition to existing government programs designed to help ensure the long-term financial security for people with disabilities,” said David Birkbeck, head, registered products strategy, RBC. “Our role at RBC® is to help educate Canadians about how these plans work and to help those eligible get the most benefit.”

## Here's what you need to know to make the most of an RDSP:

### Who can qualify

The beneficiary of an RDSP must be a resident of Canada with a Social Insurance Number, under age 60 and eligible for the Disability Tax Credit (DTC). To qualify for the Disability Tax Credit, the individual must have a prolonged and severe impairment in physical or mental function that is confirmed by a qualified medical practitioner and accepted by the Canada Revenue Agency (CRA).

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### Making contributions

Contributions to an RDSP are not tax deductible, but they grow within the plan on a tax-deferred basis. There is no annual contribution limit, but there is a lifetime limit for total contributions of \$200,000. Contributions can be made up until the end of the year the beneficiary turns 59.

### Government assistance

Contributions may be eligible for federal government matching grants (Canada Disability Savings Grants) up to \$3,500 annually, and the plan may be eligible for government bond amounts (Canada Disability Savings Bonds) up to \$1,000 annually. The money in an RDSP can be used for any purpose, as long as it is for the benefit of the plan's beneficiary.

Within Registered Disability Savings Plans, RBC clients will have access to a wide variety of investment options including RBC Funds, RBC GICs and RBC Savings Deposits. There will be no annual administration or withdrawal fees. Clients will also have the opportunity to make regular, pre-authorized contributions through RDSP-Matic™.

RBC has also joined forces with Planned Lifetime Advocacy Network (PLAN), the non-profit organization that led the advocacy for the creation of the Registered Disability Savings Plan, to help educate and offer advice to Canadians. As PLAN's preferred national RDSP provider, RBC is working closely with PLAN to assist Canadians with disabilities and their families.

For more information, call 1-800-463-3863, or visit [www.rbc.com/rdsp](http://www.rbc.com/rdsp).

For more information on Planned Lifetime Advocacy Network (PLAN) or for more about RDSPs, please visit [www.plan.ca](http://www.plan.ca) or [www.rdsp.com](http://www.rdsp.com).



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# Field of Dreams

For these players and their parents, weekly event is **more than just another game**

by LAUREN BARON

**O**n a balmy summer day in June, a group of parents gather turf-side to cheer on their children in between warm exchanges and occasional sips of coffee. Like typical soccer moms and dads, they have come out to support their kids on the field. But for these devoted parents and their exceptional children, the game represents more than just another event; it's an affirmation that their children are part of a community and a testament to the ability of parents to make a difference for their children. Parents like Theresa Grabowski of Oshawa and Abbe Gates of Vancouver, who not only identified a social inequity, but acted upon it.

It was the fall of 2007, and Gates' 12-year-old daughter Sadie had been invited by her friend Hannah to join an all-girls beginner soccer team – a team comprised entirely of “typical” kids. “They were all doing the drills and everything was perfect,” recalled Sadie's mother. “I was sitting on the park bench with a few other parents and thought ‘Oh, they're all doing so well.’ ”

Gates decided she would sign Sadie up as a permanent member of the team, but was turned down by the coach. Sadie has Down syndrome, and the coach cited Sadie's disability as a liability. “I was speechless for the first time in my life. I couldn't even talk or breathe,” Gates said. “It wasn't that she couldn't do what the

other girls could do; she was doing what all the other little girls were doing. He was just judging her on her looks, not her ability.”

Hannah's mother, Kim Pemberton, was also saddened by the decision. “In the coaches' zeal for the typical team to do well, he overlooked a much more important lesson for the other players, that is, acceptance of diversity. Sadie has a right to play in her community. The team would have been so much better if she had been included. Her exclusion was such a loss for all the girls. They lost getting to know a wonderful, future friend. My hope is that all coaches of typical teams realize the value all children bring and be open to everyone in the future,” said Pemberton.

## Mothers of invention

Determined to afford her daughter the same opportunities for fun, camaraderie and exercise as other children her age, Gates founded a local non-profit soccer league for kids and teens the very next day. Called *The Blazin' Soccer Dogs*, the league accepts everyone ages four and up, disability or not.

Today, 90 players register annually, representing “every special need you can imagine,” according to Gates – from autism and developmental delays, to visual impairments and even illnesses such as cancer. The summer soccer season in Vancouver begins in April and ends in June, and the fall season runs from September to October, with games held every Saturday morning. The kids are supervised by 10 coaches and 25 volunteers – the majority of whom are students who have been trained to deal with various behavioural issues and help players in a supportive capacity. Parents are invited to take it easy and enjoy watching their children play.

“With this team, we want parents to meet other parents and relax for that hour and a half,” said Gates. “So [often], when we [exceptional parents] put our kids into sports, we have to stay with them to make sure they are looked after. On our team, we have 25 volunteers that [watch the kids] for the parents. [Parents] can sit back, drink their coffee and socialize without a worry about their child.”

*The Blazin' Soccer Dogs* aren't the only Canadian recreational sports league that embraces players with special needs. Exceptional parent Theresa Grabowski founded *Challenge League Sports* in Oshawa back in 1993 as a means for her then eight-year-old

son Jason, who has Down syndrome, to experience the benefits of sports just as her two “typical” children had. Dedicated exclusively to players with special needs ages five and up, the non-profit league began by

head injuries. To this day, Jason continues to play on the league's soccer, baseball and basketball teams. At 23, he's considered young relative to *Challenge League's* oldest member, who is in his sixties.



PHOTO: KIM PEMBERTON

*Soccer Dogs* team-mates Sadie Gates, 12, and her good friend Hannah Pemberton, 13, pose with volunteer coach Peter Tom-Wing – also an exceptional dad.

offering baseball, then added soccer in 1999, and basketball in 2000. The playing season runs from June to August, with games held every Thursday. Players with various disabilities are included, from those with global developmental delays and cerebral palsy, to youth with Fetal Alcohol Spectrum Disorder or

In both the Vancouver and Oshawa leagues, players are divided into small groups and are taught basic soccer skills and techniques on outdoor soccer fields. Unlike the *Soccer Dogs*, however, there are no formal teams in *Challenge League*. “We don't set the teams because it [tends to] cause rivalry,” said Grabowski.

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PHOTO: THERESA GRABOWSKI

*Challenge League Soccer's junior division members and their volunteer coaches, Donna Bateman (left) and Kelly Hewitt (center), in Oshawa.*

Instead, her players wear black pants, white tops and coloured pinnies to distinguish their teams on a given day. “Sometimes you play with your friends, and sometimes you play against them,” adds Grabowski.

And no one is left out.

“The variety of their disabilities does not impact on any of the [participants’ abilities to engage in] the sports,” said Grabowski. In both leagues, players with greater needs who require assistance to kick the ball or follow directions, for example, may work individually with volunteers who might help them along on the field. On the *Soccer Dogs’* team, one-on-one volunteers carry boards with pictures of soccer balls and players kicking, as visual tools to help members understand the object of the drills.

Adaptations are also happily made for players with physical disabilities. The acceptance of a *Challenge League* player who uses a walker for mobility simply required some minor modifications on the team’s part during the games; when the ball approaches him on the field, he has five seconds

to get to it before anyone else is permitted to interfere. Over on the *Soccer Dogs’* field, 13-year-old Vivek Patel plays with a soccer ball that emits a vibrating sound when it rolls, in order to accommodate his visual impairment. His coaches and volunteers have also been trained to lightly guide him around the field by his elbows. “There is a position [available for] anyone [who] wants to play,” said Gates. “We will find something that the child can do. The kids are very, very accommodated out on the field.”

### A sense of belonging

Beyond the opportunities for peer interaction, energy release, recreation and enjoyment, the leagues offer players a chance to be included while pursuing an activity that brings out their strengths rather than their limitations. “So many people put [the children’s] challenges first and forget the kids and it’s so wrong,” said Gates. “Here, they belong.” As Gates and Grabowski both emphasize, it is this very sense of belonging that is most gratifying for players. “They feel good about being out there because in this

environment they are top dog and they have never been top dog,” explained Grabowski.

Twelve-year-old Stephen Cubitt has a form of Attention Deficit Disorder. He and his 16-year-old sister Caitlin, who has autism, love being part of *Challenge League*. “I like being the goalie,” said Stephen, who joined *Challenge League* in 2008. Having previously played soccer for another Oshawa league, Stephen would ask his coach every week if he could be goalie, but was perpetually refused – a decision his mother Beth believes was likely based on the fact that Stephen was never as fast or skilled as the other players. As a *Challenge League* player, he has the opportunity to try out whichever position he wishes, since in contrast to other recreational leagues, *Challenge League* players “aren’t pressured to win,” noted Grabowski.

Both the Vancouver and Oshawa leagues pride themselves on their commitment to offer non-judgmental, non-competitive environments where players are free to come as they are and have fun. “The [players] don’t care if you’re wearing Nike,

or if you're wearing the latest hair style. It never comes up. It's one of the amazing things about the nature of the league and the players themselves," said Grabowski.

Recognizing the tremendous opportunity for social interaction that the games provide for so many of their players, Gates and Grabowski try to encourage peer bonding and facilitate the creation of friendships when-

a lot of these kids don't have the social skills to [initiate conversations on their own]." Kids who have never been invited to a birthday party before are now high-fiving their friends out on the field and going to their parties, according to Gates.

For Stephen and Caitlin's mother, Beth Cubitt, the *Challenge League* allows her children to develop at their own pace, without being teased

## Kids who have never been invited to a birthday party before are now high-fiving their friends out on the field and going to their parties.

ever possible. Prior to the beginning of each season, the *Soccer Dogs* pass around a scrapbook that contains a picture and accompanying information about each player. "It's so amazing what a difference [viewing the book and seeing their teammates in advance] makes for all the kids, because [upon arrival at the first game,] they are [already] familiar with [each other's] faces," said Gates. "They can say 'Oh, you have a dog? I have a dog.' It's great because

by other kids who are often critical of them because of their differences. "If (Caitlin) was playing with her peers, they would be miles ahead of her [in terms of their skill levels]. With the *Challenge League* they get to talk to people who just talk to them for who they are and don't give them funny looks."

As Grabowski has observed over the years, the leagues not only provide a forum for the kids to socialize and

have fun; they also offer comfort for players' parents, who look forward to the opportunity to socialize with fellow parents and watch their kids engage in "typical" activities. "It's great for networking, and the parents feel good watching their kids have fun. When you see your kids are doing things that are "normal," it brings normalcy to your parenting," said Grabowski.

Gates agrees that the weekly gatherings are every bit as rewarding for parents as they are for their children. "[At the game,] you talk and share and you learn [with other moms and dads]. You don't have that [opportunity] in your everyday life [as an exceptional parent]. I'd never met other parents with children with special needs [until I formed the league]," Gates said. "You're there for two hours a week and you have so much to talk about [with each other]. You learn so much from [other exceptional] parents. It's an unbelievably beautiful environment."

Just like "regular" leagues, both the *Soccer Dogs* and *Challenge League* award trophies to all of their players at the end of the season, in recognition of their enthusiasm and participation. "Then they have that picture [of themselves with their trophy] on their wall like the other kids in their family. They have a trophy in their room like their brothers and sisters," said Grabowski.

And just like "regular" kids, they anxiously begin the countdown leading up to next year's season opening, when they can relive the excitement all over again. ■

For more information on *The Blazin' Soccer Dogs*, visit [www.soccerdogs.ca](http://www.soccerdogs.ca). For more information on *Challenge League*, visit [www.challengeleague.ca](http://www.challengeleague.ca).



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# Amblyopia: It's a Brain Thing

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

by LEAH WALSH, MSc, OC(C), COMT and G. ROBERT LAROCHE MD, FRCSC  
Department of Ophthalmology and Visual Sciences, Dalhousie University

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. Having also explored the condition of strabismus, including its manifestations and potential treatments in depth, the following piece will offer insights into another common childhood eye problem: amblyopia.

Amblyopia is the medical term for poor vision in an otherwise normal eye. It is the most common cause of visual impairment of one or both eyes in children, with an incidence of 1 to 4% in the general population. Amblyopia is commonly referred to as "lazy eye", however the eye itself usually appears normal. In amblyopic eyes the vision is reduced because the brain has not learned to use them. Normally we use both

eyes simultaneously to view the world. The brain fuses the images coming from each eye to form a single one. This ability to use both eyes simultaneously is actually a learned skill. Infants may be born with the ability to see, yet their brains must learn to focus and use the eyes together as a unit.

Our vision continues to develop during the so-called "critical period" in which amblyopia may occur, but fortunately can also be effectively treated. Although the timeframe for this "critical period" varies in the literature, our vision often continues to develop until we are about nine to 10 years old. If the brain does not learn to use one or both eyes during this period, the vision in the eye(s) involved will not develop normally and amblyopia will occur.

Our understanding of how amblyopia works has been made possible through the research of Drs. Hubel and Wiesel, who received a Nobel Prize for their scientific explanation of the critical period in the development of the visual system. They

demonstrated the changes that occur in the cells of the brain when one eye is amblyopic. They also showed that these brain changes could be reversible if treatment is started early.

## What causes amblyopia?

Amblyopia can occur as a result of unequal stimulation from each eye caused by image blur (a difference in the strength of lenses in the glasses in one eye compared to the other eye), different images (which may result from crossed eyes, i.e., strabismus), or poor quality of an image (from cataracts, scars at the surface of the eye due to infection or accident, or lid malformations, to name a few). Depending upon possible medical problems associated with their disabilities, exceptional children may be more prone to amblyopia, especially the type that is associated with strabismus. Such is typically the case with children who have Down syndrome, cerebral palsy or other neurological problems, as well as those born extremely prematurely. On the other hand, other



conditions are not associated with increased risk of amblyopia, an example of which is autism.

## The different types of amblyopia

Amblyopia by strabismus (*Strabismic Amblyopia*) develops when the eyes are not aligned. The eye that is misaligned can point up, down, inward, outward, or there may be a combination of horizontal and vertical

aligned, subsequently resulting in loss of vision in that eye (amblyopia).

Amblyopia by unequal blur (*Anisometropia Amblyopia* – “anisometropia-size of eye”) develops when there is either a large or unequal amount of refractive error (strength of glasses). In order to prevent the superimposition of a blurry image over a clearer one, the brain will usually suppress the image of the eye that has the higher

refractive error. The discovery of this type of amblyopia can be significantly delayed since the eyes are generally aligned and the vision in the good eye is usually normal. This situation occurs frequently if there is no screening of vision problems done in a timely fashion before the child starts school.

Amblyopia by poor image (*Deprivation Amblyopia*) develops when an eye disease such as a cataract deprives the eye of clear vision. This type of amblyopia is rare, and thankfully so, because it is more difficult to treat; first the cause of the poor image has to be treated before the amblyopia itself can be addressed. This involves surgery of the eye in question to remove the cataract or scar on the cornea (the part of the eye which is literally the window to the world) – two examples of the many causes of vision deprivation.

amblyopia by unequal blur (*Anisometropia Amblyopia* – “anisometropia-size of eye”) develops when there is either a large or unequal amount of refractive error (strength of glasses). In order to prevent the superimposition of a blurry image over a clearer one, the brain will usually suppress the image of the eye that has the higher




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## Treating the condition

A child's vision is generally fully developed by age nine or 10, therefore amblyopia **must** be treated during childhood. The younger the child, the easier it is to reverse the amblyopia. If amblyopia is not treated it will become a permanent vision problem.

Various options may be employed to treat the different types of amblyopia cited earlier. Regardless of which treatment is employed, however, the goal is always the same: to improve the vision of the bad eye by forcing its use. During amblyopia treatment, decreasing the vision of the good eye will encourage the brain to use the other eye. Interestingly, some of

the current treatment methods date centuries back. For example, ancient Arabic medical texts composed long before the rise of the Roman Empire describe methods of "forcing the bad eye to get new strength by blocking the used eye." Today, the main methods used include patching or blurring the vision of the good eye with glasses or eye drops. None of these treatment options involve actual exercises of the eye muscles because they themselves are normal; remember, amblyopia is a *brain* thing.

Amblyopia treatment has to be done carefully; for just as vision can improve in the weaker eye, it can degenerate in the good eye if too much treatment is applied.

Accordingly, children undergoing amblyopia treatment are monitored very frequently to ensure that the good eye stays strong while progress is achieved in the eye being treated.

One of the first questions often asked by parents or caregivers when their child has been prescribed amblyopia treatment is, "How long will this take?" Unfortunately this is not an easy question to answer. Every child is unique in the way he or she responds to treatment. Often, the younger the child and the more intense the treatment, the quicker the vision will improve. Once optimal vision has been reached, some children may need a form of maintenance treatment until their visual system has reached maturity to prevent the gains in vision to be lost again. This may be particularly necessary for younger children who are prone to more rapid changes in their vision due to the immaturity of their visual system.

Studies on the natural course of amblyopia if left untreated have shown that the vision of the amblyopic eye does not improve and can actually deteriorate further during childhood and adolescence. Moreover, although children and adults with the condition may be able to function adequately with exclusive use of their better eye (assuming it has normal vision), there is always the risk that something could happen to the normal eye, leaving them to rely on the poorer amblyopic eye for vision. Research has actually suggested that people with an amblyopic eye are more prone to injury in their good eye.

## A team approach

Today, ophthalmologists who care for children work with orthoptists

when they manage the treatment of amblyopia. An orthoptist is an allied health professional who specializes in the study of eye movements and visual development. The orthoptist is often given the task of implementing and modifying the treatment of an amblyopic child based on the child's response to treatment, the family dynamics during the treatment and, naturally, the child's reaction to the whole process.

The daily burden to administer treatment for amblyopia falls predominantly on children's parents or caregivers. Amblyopia therapy requires frequent visits, often resulting in significant costs to families for travel, time off work, and accommodations. This being said, if amblyopia is not treated, there will be a lifetime of preventable poor vision in one eye. Children with poor vision in one eye are at a greater risk of developing strabis-

mus (eyes that are misaligned) with resulting decreased or absence of depth perception (3-D). It is also important for parents to remember that this ocular disorder is very treatable if detected early. The amblyopic eye is a perfectly healthy and normal eye just waiting for the brain to learn how to use it to its full potential. ■

*For additional insights on the profession of orthoptics, visit The Canadian Orthoptic Society website at: [www.tcos.ca/english/index.php](http://www.tcos.ca/english/index.php)*

**Leah Walsh** has been a clinical orthoptist and instructor for the past 16 years. The majority of her career has been spent at the IWK Health Centre; however, she spent two years working at the world-renowned Wilmer Ophthalmological Institute at Johns Hopkins

Hospital in Baltimore, Maryland. In addition to her clinical role, Ms. Walsh is an Assistant Professor in the Master of Science: Clinical Vision Science Program at Dalhousie University.

Following completion of an ophthalmology residency at Laval University in Québec City, **Dr. Robert LaRoche** (MD, FRCSC) continued his training in pediatric ophthalmology and strabismus surgery both at McGill University in Montréal and at Baylor College in Houston. He is now Professor of Ophthalmology at Dalhousie University in Halifax where he continues to be involved in clinical and research activities on strabismus and amblyopia as well as in the supervision of many post-graduate Canadian and foreign students.

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Montreal Children's Hospital  
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# In

# Focus

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

## Fundamentals of Evaluation and Treatment of Children with Special Needs – Part II



PHOTO: JULIAN HABER

In the first of this two-part series, we discussed what parents can do when they suspect their child might have a problem that needs profes-

sional intervention. We explored the importance of seeking an evaluation in order to give the problem a name (the diagnosis) and in order to understand how the problem gives rise to your child's unique combination of strengths and weaknesses.

### I have a diagnosis; now what?

Once you have arrived at a diagnosis for your child, the next step is to begin seeking interventions or therapies to treat the problem. Depending upon your child's diagnosis, you may discover an overwhelming number of treatment options. And very often, proponents of a given treatment will argue convincingly and sincerely that theirs is the best choice. So how's a parent to decide? Do you listen only to the advice of your child's doctor or teacher, for example? Do you also turn to your best friend, your mother, a chat room, or that nice lady you met at the new support group? Eastern medicine or western? A change of diet? Vitamins, homeopathic remedies, naturopathic supplements, or pharmaceuticals? What about therapies: ABA? RDI?



Speech? OT? Some combination of these? How much is too much? How much is not enough?

If you feel you don't know which way to turn, take heart. Your reluctance to arbitrarily settle for the first therapy suggested to you without investigating all options simply means that, like any concerned parent, you're aware that the stakes are high – this is your child's health and happiness you're taking responsibility for. There would be more to worry about if you *didn't* feel that way!

So who do you listen to? Everyone. That doesn't mean you have to take everyone's advice. But it's good to

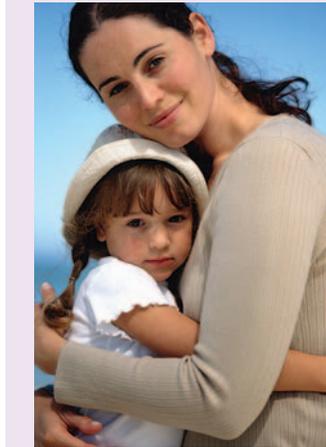
be aware of all possibilities, even if some are quickly ruled out. The most important voice to listen to, however, is your own – that inner voice telling you when something feels right or wrong.

### Develop an individual treatment plan

Your job now is to develop a treatment plan – a set of interventions or therapies designed to help your child achieve short- and long-term goals. While the goals and intervention methods of the plan may change over time, there should always be a master plan describing past, present and potential future

treatments. Your first instinct may be to follow a treatment plan that seems to be working for another child. But remember that although two children can have the same diagnosis, each may have a com-

pletely different set of strengths and weaknesses. What works for one child may not work for yours.



**Treatments and therapies** don't all have to constitute intensive sessions of hard work. Therapies that do nothing more than make your child feel good about him or herself have a place in your child's treatment plan too. One mother I know includes regular "salon therapy" sessions for her daughter, in which she's pampered at a local salon – an experience her mother describes not only as a confidence booster for her child, but also one that yields more joy for her daughter than any of her formal treatments.

Nor should you expect any one doctor, therapist, or practitioner to develop and oversee a multi-modal treatment plan (one that encompasses different disciplines) for you. A child with special needs very often needs help in several different areas. And while professionals may be experts in their own fields, they may be no more knowledgeable than you are about the others.

An exception that may be made for one individual to oversee an entire treatment plan would be in the case of a professional whom you have chosen to act as a case coordinator – someone who may advise you and help you to manage your child's treatment plan. A case manager may be particularly helpful if you ultimately find yourself juggling a number of different treatments targeting a complex set of problems. At this early stage, however, your

first step is to gather all the information and advice that you can from trusted sources, and then to start developing an individual treatment plan that makes the most sense for you, your child, and your family,

beginning with a single treatment. While this task may seem daunting, there are effective problem-solving strategies that can help you along the decision-making process:

include motor, communication or learning problems, among others. Social-emotional behavioural problems are frequently part of the mix as well. List them.

**2. Prioritize** – Recognize that you can't attack everything at once. Number the symptoms or behaviours you'd like to address in order of priority. Remember to consider not only your child with special needs, but the rest of the family as well, when delineating these priorities. Certainly anything of a medically-urgent nature should top your list. Otherwise, addressing a problem that creates stress on everyone in the family might be your first choice, since resolving that issue will free up more time and energy to devote to other problems. Alternatively, your family may be able to cope with the needs of your exceptional child at home, and your priority might be to deal with a problem that's interfering with your child's functioning at school.

However you choose to rank these problems, don't let this first step tie you up in knots. You're not engraving



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ing your list in stone; priorities can change. You might start working on the first item on the list, for example, and find it too daunting, or discover there's a long waiting list for a particular intervention. In that case, you'd want to move on to the next item. The point is just to get started. Whether you're heading down one path or another isn't as important as taking those first steps.

**3. Break the problem down into smaller parts** – If the problem is communication-related, for example, you would want to pinpoint exactly where the problem lies. Does your

child have difficulty expressing him or herself to others, or understanding what others are communicating? Can your child communicate verbally but is incapable of expressing him or herself nonverbally, or the reverse? Once you have clearly dissected the problem, you're ready to take it on.

**4. Identify treatment options** – Use the internet, talk to friends and professionals, and contact community support groups and national organizations in order to research potential treatment options for your child's particular issue(s). Get as

much information as you can – good, bad, and ugly. Exactly what does the treatment or therapy entail? What results are realistically achievable? What are the risks? At what point might you expect to see results (or determine that the therapy in question is not working)? Is it available in your area? What does it cost? What kind of time commitment does it entail? Regardless of how successful the program may have been with other children, does it make sense for yours? Although the treatment may have been designed to address a problem your child has, the same challenge may have several potential causes and the program in question may be more successful treating some causes over others. Or your child might have a secondary problem that would prevent him or her from reaping the full benefit of this particular treatment.

Whenever possible, and certainly when it's an option you're seriously considering, try to arrange to meet with your child's potential therapist or practitioner together with your son or daughter. It's as important for them to learn about your child as it is for you to learn about their program. After meeting one another and interacting for a period of time, both of you should have a better indication whether this seems like the right fit.

**5. Select a treatment or therapy** – At this stage, you might have a number of options to choose from. While in the future your child might engage in two or more treatments concurrently, for now you should just begin with one.

If you have trouble deciding between various options, you may find it helpful to draw up a list of pros and cons associated with each option. Write down everything you can

think of, from the most minor consideration to the most significant. Assign every item on the list a value from 1 to 5, representing how much weight it should carry in the final decision. For example, a therapy that carries a significant risk would belong in the cons column, with a higher score than you'd give to a treatment that, at the very worst, could do no harm.

Now add up the scores. Subtract the total in the cons column from the total in the pros column. If the cons outweigh the pros, the result will be a negative number. That option would clearly not be your first choice, and you may even wish to eliminate it from the list of potential treatments. The option with the highest positive number is probably the one you will want to try first.

**6. Give it a fair shot, then assess** – In Steps 4 and 5, you established the

goals you wished to achieve from this treatment and learned how long it might take to see results, or ascertain that the treatment isn't effective. Reaching such a conclusion isn't an exact science and children often respond at different paces, but at some point you'll probably have a good idea whether you want your child to continue this treatment or try another intervention.

**7. Rinse and repeat** – At this stage, you might choose to switch to another treatment or decide to add a second one, by retracing the above steps. This process may continue for years, adding and subtracting programs and therapies as your child reaches new milestones, new treatments emerge, or new challenges present themselves. As mentioned earlier, eventually your child may be benefitting from several simultaneous treatments. But it's always preferable to add them gradually,

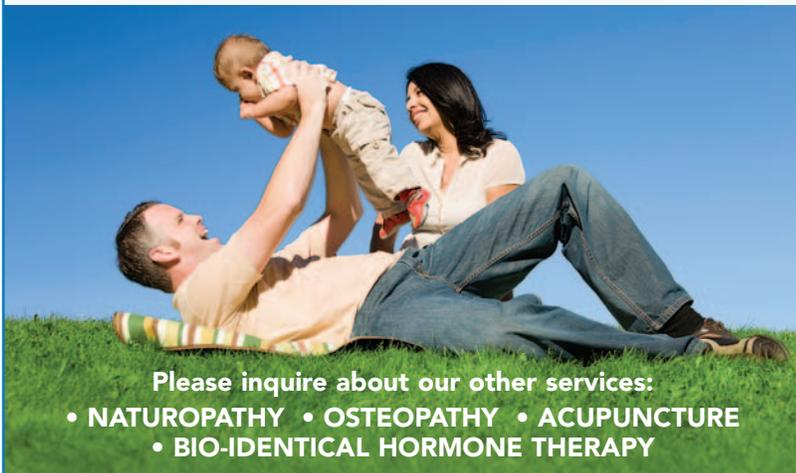
one at a time, so you can make an accurate assessment of which treatment is responsible for which improvement – or if one is making no difference at all.

By following these steps, you should soon start to feel confident in your ability to develop and maintain a treatment plan that will yield benefits for both your child with special needs and your family as a whole, for years to come. ■

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

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# Just Take a Bite!

## Easy, Effective Answers to Food Aversions and Eating Challenges



*The third article in  
Exceptional Family's  
unique Food For  
Thought series*

by LORI ERNSPERGER, Ph.D

Sharing a meal with family and friends can be a most rewarding and life-affirming activity. There is nothing more satisfying than a lazy morning brunch, a picnic in the park, celebrating with holiday treats, or lunch with friends in the school cafeteria. Eating and sharing a meal is a wonderful experience unless you are a resistant eater or you have a resistant eater in your family. Then eating and mealtimes are often stressful, chaotic, and involve constant negotiation. Mealtimes and celebrations can soon turn disappointing over unfulfilled expectations and dashed hopes when a resistant eater refuses to share a meal with family and friends.

### Who are Resistant Eaters?

Resistant eaters are a mixed group and include a myriad of characteristics. Some resistant eaters have medical issues or physical impairments, while others have a sensory integration disorder or poor oral-motor skills and have not developed appropriate tongue control, chewing and swallowing skills. There is not one single characteristic to identify resistant eaters. For the purpose of this article, the term “resistant eater” applies to any individual who exhibits one or more of the following characteristics:

1. Limited food selection. Eats a total of 20 foods or less.
2. Limited food groups. Refuses one or more food groups.
3. Anxiety and/or tantrums when presented with new foods. Gags or becomes ill when presented with new foods.
4. Experiences food jags. A food jag refers to the insistence on the same food, the same utensils, or even the same setting over long periods of time.
5. Diagnosed with a developmental delay such as autism, Asperger syndrome or Pervasive Developmental Disorder-Not Otherwise Specified.

Due to the variety of defining characteristics of resistant eaters, an assessment should be conducted by a multidisciplinary team which includes the parents, teachers, therapists and physicians. Depending on the individual needs of the child, several factors may be contributing to problems with eating, including food neophobia or fear of new foods, environmental factors, cultural beliefs, oral-motor delays, and Sensory Processing Disorder. A thorough review of the child's medical history and assessment of oral-motor delays by trained professionals is necessary before beginning a treatment program. A collaborative team approach to assessment and treatment will ensure that a written plan is implemented across settings and throughout the child's day.

## A comprehensive treatment plan

Solving the mealtime dilemma is not a quick fix. For most parents, the goal of any eating program is to "get the child to eat more food." Although increasing the variety of foods the child eats is an important secondary goal, the main focus of this article is to provide children and families with a positive mealtime experience and support them as they explore new foods.

Each child who experiences problems with eating is unique and therefore requires an individualized plan to meet his or her needs. A comprehensive treatment plan includes a multilevel and multisensory approach that requires a commitment from parents and the professionals working with the resistant eater. For school-age children, it is important that the school team creates opportunities to implement the plan during the school day.

Although each child is different and the goals for the treatment plan must reflect the unique characteristics of the child, there are some general goals for all treatment plans. These include:

1. Creating a safe, positive, and nurturing mealtime environment.
2. Expanding the child's responsibilities in preparing, consuming, and cleaning up at mealtimes.
3. Improving the child's oral-motor development.
4. Addressing all physical needs of the child during eating.
5. Providing multisensory exposure to new foods.
6. Respecting the child's communication and response to eating.
7. Expanding the child's repertoire of foods and creating a balanced diet.

It is important to remember that the plan is not intended to be an adverse or punitive program that

forces or bribes the child to eat. The focus is on exploration and learning about new foods and eating.

The first area to address in the treatment plan is **Environmental Controls**. Environmental controls are the foundation for a solid treatment plan. In order for the child to learn about new foods, the mealtime environment must be positive and nurturing.

As such, the following guidelines and strategies for structuring the environment may prove useful:

1. Design a consistent schedule that includes all meals and snacks. The schedule should be posted and a timer used to define the length of time that the child must stay seated. Children who struggle with eating a balanced diet should only eat meals and snacks according to the schedule.
2. Select an appropriate setting with minimal distractions. The kitchen table is the most appropriate setting for a meal. Some modifications may be necessary depending on the child's age and size.

### Summer Camps for Children with Special Needs

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- **Living It Up! - Life Skills Camp**  
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- **Chatterbugs - Articulation**  
For children ages 5-6 years whose primary challenge is articulation.

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Children should eat all meals and snacks at the designated setting.

3. Create a supportive climate with written, age-appropriate rules. A supportive environment respects the child and does not allow adults to invade the child's mouth without permission. Never discuss the child's eating habits or how much he eats during the meal. If inappropriate behavior is exhibited during the meal, remove the child from the table letting him

know that his behavior is sending a message that indicates he is not hungry. The family should finish the meal and the child may receive a snack according to the schedule.

4. Select one menu for the entire family. A family meal should include a protein or meat, starch, fruit, and/or vegetable, and milk. When planning a family menu, consider selecting child-friendly foods. Always provide the resistant

eater with at least one serving size of a preferred food item. Use child-friendly portions. Consider using a smaller plate to encourage child-size servings. A smaller portion allows the child to see the results when taking a few small bites.

5. Address food jags. Do not cater to the child's rigidity in wanting the same foods. Make slight changes in the presentation of the food or change the brand names. Be sure the changes are small and do not create anxiety for the child. Provide the child with limited choices (as in, "Would you like cucumbers or carrots?") for food items and/or utensils.

The second part of the treatment plan focuses on **Physical and Oral-Motor Development**, concepts we will explore in greater detail in the next issue of *Exceptional Family*. ■

**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](mailto:drlori@cox.net).

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# Exceptional News

News briefs highlighting special issues

## Filmmaker's sci-fi stunt is truly eye-opening

A Toronto filmmaker plans to shoot an undercover documentary on the worldwide use of public surveillance cameras with a camera hidden inside his prosthetic eye. Rob Spence, 36, lost his eye in a childhood accident involving fire-arms. He wore an eye

Rob Spence

PHOTO: JONAS ST. MICHAEL



patch until 2002, when the organ was replaced with a prosthesis resembling his real eye in both colour and shape. The idea to conceal a camera within came to Spence after he examined his cell phone camera and realized that an equally small apparatus could be constructed to fit into his eye. Unable to fund the project himself, Spence publicized his idea and was met with enthusiasm from people happy to contribute – including engineers at Massachusetts Institute of Technology who offered their expertise. The one millimetre camera contains a wireless transmitter and a battery, and Spence will be able to move it with the muscles in his eye-socket.

While reactions to his plans have varied from fascination to discomfort and even fear, Omnivision, the company supplying the camera, believes that the project's success may inspire future exploration of the technology's potential to restore vision to people who are blind.

## Couples in no hurry to have children may want to reconsider

Researchers in Australia and the US have found that children of older fathers are more likely to be less intelligent than those born to younger ones – information that is particularly relevant to the growing number of couples intentionally delaying to start a family. As published in the American journal *Public Library of Science Medicine*, the scientists studied the intelligence test results of over 33 000 American children whose fathers ranged in age from 15 to 65. The tests were conducted by the US Collaborative Perinatal Project (CPP) between 1959 and 1965, when the kids were eight months, four years, and seven years old. Cognitive functions that were assessed included the children's abilities to think, learn, understand, speak, remember, concentrate and reason.

While previous studies have linked children of older fathers with an increased risk of developing birth defects, dwarfism, dyslexia, autism, cancer and schizophrenia, the most recent findings suggest that the older a father is, the less intelligent his child will be – regardless of the father's mental health, level of education, or income. There is speculation that the frequency with which men's sperm-making cells divide as they age makes the cells more prone to damages and mutations. Since the study was limited to seven-year-olds, it is not known whether children of older dads can catch up to their peers in intelligence tests as they mature.



PHOTO: KOSTA GRAMMATIS

Camera and prosthetic to scale.

## Extreme weather having an effect on unborn children

Pregnant women who are subjected to emotional stress during natural disasters predispose their unborn babies to a host of medical conditions including autism, lower IQ's, high blood pressure and obesity, according to a panel of international researchers. At a recent conference sponsored by Montreal's Douglas Mental Health University Institute, the panel presented findings on the long-term implications of extreme weather events like hurricanes, tsunamis, ice storms and floods, on children's neurological functioning and mental health. Dr. Suzanne King, director of the Psychosocial Research Division at the Douglas Institute and associate professor of Psychiatry at McGill University, shared the results of IQ and language tests conducted on approximately 180 children born after the 1998 Quebec ice storm. The IQ's of kids whose mothers had experienced extreme stress during that period were 15 points below average. King also shared findings from a second study which found a correlation in the prevalence of autism in children whose mothers had experienced hurricanes in Louisiana during their second trimester of pregnancy.



## Woman with seeing-eye horse rides high in the face of controversy

A Texan woman who uses a seeing-eye horse to perform daily activities and get around the city is stirring U.S. federal legislators to rethink a law that permits service animals of any kind to accompany their users anywhere they go. As featured on ABC News, Tabitha Darling, a professional horse trainer, is legally blind and has hip and leg problems. While she has some vision, she cannot drive and relies on her 15-year-old pony, Trixie, for mobility – stopping at local Drive-Thrus and



Tabitha Darling with her pony, Trixie

even entering grocery stores and retail outlets like Target while mounted on her horse. Under the Americans with Disabilities Act (ADA), businesses that serve the public must "allow people with disabilities to bring their service animals onto business premises in whatever areas customers are generally allowed."



Adam Cunningham

## Surgery may prove curative for some people with epilepsy

Thousands of Canadians who have a common form of epilepsy may be missing out on potentially curative surgery simply because they are unaware that it is available. According to Dr. Taufik Valiente of Toronto's Krembil Neuroscience Centre, every year only 300 out of the 20 000 Canadians who experience partial seizures opt to undergo an operation in which small sections of the brain are removed with the aim of interrupting the circuits that trigger the attacks. CTV News recently shared the story of 31-year-old Adam Cunningham of Burlington, Ontario, who underwent the surgery in December at Toronto Western Hospital. Cunningham



began experiencing mild seizures at eight years old which caused him to become confused and lose awareness, and he would often forget that they had even occurred. Because the seizures were subtle and never sparked uncontrollable jerking, Cunningham's condition went undiagnosed until he was 30. Despite the 1% chance that he would be left paralyzed following the operation, Cunningham went ahead with it on the 80% chance that it would result in the elimination of his seizures with zero side effects. Six months later, Cunningham remains completely seizure free.

# A sunny place for children with FASD

Camp offers invaluable support to families affected by Fetal Alcohol Spectrum Disorder

by WENDY HELFENBAUM

Many parents send their children to day camp hoping they'll learn to swim, perform in a play, or try their hand at pottery-making. But for a growing number of Calgary families, an innovative program called Stepping Out On Saturday (SOS) has proven to be a lifesaver.

Renfrew Educational Services, a non-profit organization offering a range of specialized programs for children with special needs, is also home to SOS, a full-day camp catering exclusively to children aged 3-12 who have been diagnosed with Fetal Alcohol Spectrum Disorder (FASD). FASD refers to a range of physical and/or cognitive disabilities that may affect a person whose birth mother drank alcohol while pregnant. Health Canada estimates that nine in every 1,000 babies born in Canada have FASD – the leading form of developmental delay in North America.

Some common, usually permanent anomalies associated with FASD include facial abnormalities, memory and attention span problems, learning disabilities, difficulty communicating emotions, and problems understanding the consequences of



*Eight-year-old Laura participates in one of Renfrew's many creative activities.*

actions. Other challenges that may develop as children with FASD mature include difficulty interacting with others, low self-esteem, poor impulse control, drug or alcohol abuse and inappropriate sexual behaviour. Teenagers with FASD often behave like children half their age.

Alberta Health Services estimates that one baby with FASD is born each day in the province. Birth and foster parents face enormous hurdles finding adequate childcare, therefore

rarely get any time to themselves. In the late 1990s, Calgary's Family Services Authority carried out research revealing there would be fewer breakdowns in adoptions or foster care placements if parents and caregivers were given adequate support. Faced with the growing need for respite care, Renfrew launched its SOS respite camp in May 2002 with partial funding from United Way.

Karen Vint, a speech assistant and child development facilitator, took over as SOS camp coordinator in January 2009. She says one of SOS's main goals is to provide stable, supportive environments for families and children with FASD.

"Eighty per cent of our kids are in foster care; the rest are with birth parents or family," notes Vint. "Most of these children don't know that they have FASD. They come in with all these different needs, and we try to reach the key problems that the children are facing. When kids come to our camp, they're loved, accepted and supported."

SOS runs year-round three Saturdays each month, offering children a chance to make friends while learning valuable social and problem-

solving skills, as well as coping strategies to deal with their individual challenges. The \$100 per-session fee is subsidized for most families by government grants.

Because children with FASD are easily distracted and tend to be sensory-sensitive, controlling their learning environment is key, says Vint. “We make sure the rooms

children with FASD really respond to visual support,” explains Vint.

A typical day begins with socializing or games, followed by circle time, where the facilitator announces the social skill to be worked on that day. “Children with FASD have a hard time picking up social cues and building social relationships, so we really emphasize that to build up their confidence,” says Vint. In addition to learning the meaning of “being a good friend”, campers explore the concepts of turn-taking, winning and losing, and the importance of respecting others’ personal space as well as guarding their own. The kids are also taught the skills needed to respond appropriately to teasing or bullying by their peers. “There are so many unspoken rules [in life] that are not always apparent to children with FASD, so they have to be taught and used in various settings in order for the children to be able to incorporate the social skill within their lives.”

The children receive tokens whenever they apply a given day’s skill, which they may then use to purchase a small item before they go home. “It helps them stay motivated and on track throughout the day; it’s really great for their self-esteem,” says Vint.

Facilitators alternate between gross and fine-motor activities, and also build in time for quiet stretching or relaxation exercises. “Kids with FASD have a lot of extra energy, so we go into the gym or sensory integration rooms, where the kids use swings and ball pits, which helps with their ability to self-regulate. When we see that a child needs a break, we can offer them different options to get rid of that extra energy.”



*Seven-year-old Chase tries out Renfrew’s playground equipment.*

Campers are either already enrolled in Renfrew’s preschool or grade school programs, or have been referred through social workers or Alberta’s Family Support for Children with Disabilities program. Depending on the needs and strengths they present, the children are either grouped according to age or skill level, with a general ratio of one trained facilitator for every two campers.

don’t have a lot of visuals on the walls. The lights are low, because sometimes bright lights can be irritating for children with FASD. We put soft music on in the background, to simulate a very calming and secure environment for the kids.” In order to ensure that campers have a clear understanding of the expectations at SOS, the facilitators post written and picture schedules on the walls “because

An advertisement for 'art-enfant'. On the left, there is a cartoon illustration of a child's face with hands raised. To the right of the illustration, the address is listed: '4968 Sherbrooke St. W. corner Claremont (514)488-1022'. Below this, the logo 'art-enfant' is written in a stylized font. Underneath the logo, the text reads: 'We know kids and we know toys. Let us help you find the toys your child needs to build learning skills and have fun.' At the bottom left, the website 'www.art-enfant.ca' is provided. At the bottom right, the text 'Toys and games' is displayed. On the right side of the advertisement, there is a photograph of a young girl in a pink dress playing with toys on a wooden table.

Throughout the day, facilitators write down the strategies used with the children, indicating which ones worked and which didn't. Reports get sent home to parents, who can then use the same methods themselves. "[SOS] is not just a camp to come to and have fun. We teach the children skills that will help them

just rest. It's my breath of fresh air," says Tarnowski.

Tarnowski has rave reviews for SOS staff and the results they've achieved with his son. "At school, AJ had trouble interacting with other children because he didn't understand personal space," he explains. "At

Recently, AJ became a peer leader, assisting facilitators with some of the younger campers. "AJ's self-esteem increased and his communication, [awareness of] personal space, interaction and sharing skills improved enough for him to earn sufficient tokens to exchange for a meaningful toy [at the camp]," reports Tarnowski. "It's not the prize that was important. What impressed me most was AJ's accomplishment of winning these tokens. He had to be on his best behaviour with the other children and cooperate with the supervisors. He was very proud of this accomplishment. So was I."

**"At camp, they assisted AJ with social skills, helped him learn to share and how to communicate his feelings. He likes it."**

handle their emotions," says Vint. "I've seen what a difference the early intervention makes, and the importance of consistency between home and our camp."

### **A father and son team**

Single dad Alan Tarnowski works hard to maintain that consistency with his son AJ, 12, who was diagnosed with FASD while in kindergarten after his teacher noticed he lacked social skills and wasn't performing as well as the other children. "AJ's a good kid. He's kind, polite and nice to be around most of the time, but he still gets in trouble, and it's been quite a challenge," admits Tarnowski, adding that AJ can't read or write. "He's in a public school, and I know the kids at school tease him, but he won't back down from them. He'll stand up for himself, take it head-on, and then deal with the consequences later."

Since AJ began attending SOS camp three years ago, Tarnowski has gratefully spent his free Saturdays shopping for groceries, or catching up on work or house-cleaning. "This free time is also a stress reliever; I can wind down and

camp, they assisted AJ with social skills, helped him learn to share and how to communicate his feelings. He likes it, and everything he does there is fun. The last time he went [to camp], they built a volcano, set it off and watched it bubble and he was thrilled with that."

Tarnowski believes the SOS camp is an invaluable community initiative because "it's not just a camp where they go off and play; they actually learn life skills. AJ brings those skills to school, which helps with his social environment also."

### **A helping hand for a devoted foster parent**

Allyson Dann has lovingly cared for Michael\*, 9, since he was eight months old. "When I got him, he'd already been passed along the system quite a bit," recalls Dann, who has fostered nearly 30 children as a single parent. "Not only was he FASD, but because he'd also been born with a cleft palate, he had high medical needs and was tube-fed, which just added



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\* Name changed upon request.



*Liz Raubach works on social skills with SOS campers, with the help of some puppet friends.*

to the attachment issues that [many of] these kids already have.”

Communication has been a huge challenge, because Michael has significant language delays. “He didn’t have a vocabulary of 20 to 30 words until he was about three. It was very frustrating for both of us to try and figure out what he wanted and needed,” recalls Dann.

Since Michael started SOS camp four years ago, Dann has welcomed her time off, along with Michael’s improved skills. “It takes a while to see progress, because Michael needs

so much repetition. I try and practice the same things that they practice, and I’m really starting to see some change in terms of his ability to express himself in full sentences. The biggest frustration for me has been not [being able to have] a logical discussion with this child. Now we can start to talk about what he’s doing, about anything. It’s a huge success.”

Vint has worked with both AJ and Michael since they started camp, and has been thrilled with their progress. “Both boys have gained a lot of skills, and they’ve been a big

## Additional FASD resources

**Public Health Agency of Canada’s site has basic information on FASD, as well as news and links to resources:**  
[www.phac-aspc.gc.ca/fasd-etcaf/index-eng.php](http://www.phac-aspc.gc.ca/fasd-etcaf/index-eng.php)

**Links and resources from FASworld Canada, a Toronto-based non-profit organization dedicated to reducing FASD:**  
[www.fasworld.com/links.asp](http://www.fasworld.com/links.asp)

**Parent Support Groups in Canada:**  
<http://depts.washington.edu/fadu/Support.Groups.CA.html>

**Comprehensive list of FASD websites:**  
[www.come-over.to/FAS/faslinks.htm](http://www.come-over.to/FAS/faslinks.htm)

**Health Canada’s website:**  
[www.hc-sc.gc.ca/hl-vs/iyh-vsv/diseases-maladies/fasd-etcaf-eng.php](http://www.hc-sc.gc.ca/hl-vs/iyh-vsv/diseases-maladies/fasd-etcaf-eng.php)

asset to our camp. It’s been a joy to work with them.”

Dann adds that parents should never feel guilty about wanting time off. “With a lot of children who have FASD, it’s kind of like banging your head against the wall. Repeat, repeat, and repeat. But they’re going to get it when they get it. It’s very frustrating, and that’s why taking care of you is almost as important as taking care of them. You need to take appropriate respite wherever you can get it and not feel bad about that. [The SOS camp is] a positive experience, and [I’m] sure Michael’s doing fun things while he’s gone.”

For Tarnowski, SOS camp has provided some much needed balance in his life. “It just gives me some breathing room, a little bit of a time out. And the most important thing is when AJ comes home; it helps him a lot [to function in the outside world]. And when it helps him, it helps me.” ■



# Sure I can

A column dedicated to *living & succeeding with a disability*

## Integrating Exceptional Children into Summer Camp



PHOTO: JULIAN HABER

by MICHAEL LIFSHITZ,  
CA, MBA

As the school year comes to an end and we eagerly anticipate the summer ahead, many kids are undoubtedly looking forward to leaving the rigidity of their classrooms for the more carefree environment of summer camp. Reflecting upon the summers of my own youth, I did not have many camp experiences as my summers were largely spent undergoing or recovering from surgeries<sup>1</sup> deliberately scheduled during vacation in order to minimize my absence from school.

One surgery-free summer, however, when I was eight, my parents attempted to enroll me in a local “mainstream” Montreal day camp only to be told that the camp would be unable to accommodate my special needs (the camp’s daily swim took place at a local pool 10 minutes away by foot – too great a distance for me to walk at the time).

Undeterred, my parents then tried to register me in a day camp offered by a local rehabilitation facility for people with physical disabilities.



The problem then was that because I was capable of walking independently and not confined to a wheelchair, I was not considered “disabled enough”. As my parents learned, the spots were reserved exclusively for children who used wheelchairs.

And that is when I developed what I call the Goldilocks complex – too disabled, or not disabled enough, but never just the right amount of disabled.

Determined to get me into an activity where I could socialize with other children, my parents signed me up

for an eight-week computer camp; an environment where my physical disability didn’t pose an issue. The setting not only enabled me to meet and interact with peers my own age, it also allowed me to develop functional programming and typing skills on the side.

That was 1984. Seven years later, in the summer of 1991, I registered to work as a CIT (counsellor-in-training) at a local Y day camp and was glad to see campers with marginal developmental disabilities integrated within the standard program. What seemed to have been lacking at the

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

time, however, was adequate formal training for staff members on the subject of relating to exceptional children. I recall the parents of one child with Down syndrome refusing to have a shadow accompany their child. This put a significant strain on staff, as we lacked both the experience and the training to deal with the child's special needs.

In my interviews with a number of camp directors for this piece, the common point expressed by all was

## The most important “skills” needed to work with exceptional children are empathy and compassion – abilities that are not necessarily learned in a formal educational setting.

that having an adequately trained and specialized staff is critical to the success of any integrated camp program. One camp which has achieved such success is Camp B'nai Brith, a sleep-away camp located in the Laurentians region of Quebec. Its integration program for children with developmental disabilities such as autism, ADD/ADHD, Down syndrome and Asperger's was launched in 1991 with “the philosophy that there would be complete integration,” notes Frank Weinstein, executive vice president and camp director of B'nai Brith. Today, the camp welcomes between 25 and 40 exceptional campers each summer.

According to Weinstein, exceptional campers are encouraged to take advantage of everything the camp has to offer, including participating in all activities, interacting with typical peers, and even sleeping alongside them in the same bunk. Campers who require full-time support are assisted by a shadow at all times including overnight, in order to maximize their comfort and inclusion. Prior to the start of camp, counsellors and staff who have exceptional campers in their

group are provided with sensitization training, in preparation for potential issues that may arise. A trained special needs coordinator and team of special needs staff offer additional support to counsellors and others. Staff-in-training (16-year-olds) who express an interest in working with exceptional campers are given the opportunity to work with special needs staff and, upon proving their competency, may be hired back as special needs staff the following year.

Yet the most important “skills” needed to work with exceptional children, as Weinstein maintains, are empathy

and compassion – abilities that are not necessarily learned in a formal educational setting.

Beyond staff members' sensitivity, the program also relies on “mainstream” parents' cooperation in order to run smoothly. While some parents initially expressed concern over the presence of an exceptional camper sharing a cabin with their typical children, Weinstein notes that over the years parents have actually come to appreciate the integration program, expressing joy in their children's increasing desires to care for others and assist their fellow exceptional campers in particular.

On an unfortunate note, however, Weinstein points out that the integration program at B'nai Brith is currently unable to accommodate campers with physical disabilities. While at one point the camp was able to transport campers with mobility impairments throughout the grounds on golf carts, the carts have since become inoperable and are presently too costly to repair. The grounds do have a number of accessible cabins, and Weinstein hopes the possibility of including campers with physical disabilities will be reopened in the future.

Despite the challenges involved in integrating children with physical disabilities, one still has to applaud B'nai Brith and other camps like it for their continuing efforts to include exceptional campers in summer fun.

Have a wonderful...and integrated summer! ■

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

*The second in Exceptional Family's two-part look at*

# Hearing Parents and the Child Who is Deaf

## The Pathological vs. the Socio-cultural Model of Deafness

by J. FREEMAN KING, Ed.D.  
Director, Deaf Education  
Utah State University  
Logan, Utah

In the Spring 2009 issue of *Exceptional Family*, we explored ideas for assuring the educational, social, and linguistic success of children who are deaf. In this issue, the focus will be on assisting the deaf child to establish an identity as a Deaf<sup>1</sup> person that will afford him/her the opportunity to be a vital, contributing member of both the Deaf and the hearing worlds. Of major importance is that the deaf child be afforded the human right of being Deaf – of establishing an identity of which he/she can be proud, of having a fully accessible language that can lead to literacy in the written language, and to be allowed to dream and realize his/her dreams just as his/her hearing counterparts are encouraged and allowed to do. To accomplish this, how the child's parents view deafness is extremely important: Is being deaf viewed as a disability, a defect that must be remedied, or as a socio-cultural difference? The parents' and the professionals'



answers to these questions can be the determining factor in the overall development and ultimate success or failure of the child who is deaf.

There are basically two ways in which deafness can be viewed: either as pathology or as a socio-cultural difference. Statistics indicate that 90% of deaf children have hearing parents, and these parents often view their deaf child as being disabled and immediately identify with the pathological model because they have erroneously been led by professionals to view it as such. Deaf parents, on the other hand, tend to view their deaf child in a totally different light – they fully understand

that if given an appropriate education and an accessible language in the least restrictive environment, their child can achieve whatever he/she might dare to dream.

When deafness is viewed as a pathological condition, a defect, or a disability that distinguishes abnormal from normal, there are inherent low expectations that accompany these terms. However, when deafness is considered a difference that distinguishes normal Deaf people from normal hearing people, expectations are immediately raised, and the process of labeling that follows the child throughout his/her life is minimized, or at best, eliminated.

<sup>1</sup> The word deaf is spelled with an upper case "D" when it refers to socio-cultural-linguistic identity, i.e., to an affiliation with the culture of the Deaf. It is spelled with a lower case "d" when it refers to audiological deafness, i.e., the condition of being deaf.

One might ask whether the two views are mutually exclusive or if viewing deafness as a socio-cultural difference fosters living in denial. The answer to both questions is a resounding, “No!” The person who is deaf can also be Deaf by embracing the language, culture, and societal expectations of the Deaf community. This in no way segregates him/her from the hearing world; rather it provides a socio-cultural group with which he/she can interact meaningfully and deeply, while at the same time being a member of the larger hearing world. Certainly, the hearing world’s perception that the child is disabled should be discussed with him/her: “Yes, you have challenges that hearing people do not have. Yes, you will experience discrimination and misunderstandings because you are deaf.” However, parents can reinforce the idea that being deaf does not prevent the child from doing and becoming whatever he/she wishes to do and become. As to denial of the fact of being deaf, rather than denial, viewing deafness as a socio-cultural difference opens the door to fluid and meaningful communication with the Deaf world and Deaf peers, while at the same time, being skilled in reading and writing opens the door to accessing the hearing world.

### Technology and its impact on the child who is deaf

The pathological model of deafness focuses on a cure or the amelioration of the sensory impairment, whereas the difference model emphasizes abilities and equalities. The pathological model embraces the idea that primary attention must be given to hearing aids, cochlear implants, and other devices that enhance auditory perception and/or focus on speech. The difference model, on the other hand, focuses on issues of

communication access of a deep and meaningful nature: visual devices and services such as videophones, TTYs (teletypewriters), video relay systems, TV captioning, light signal devices, interpreters, and relay operators.

The assumption of the general public, some professionals in education and medicine, as well as parents, is that technological advances such as hearing aids and cochlear implants will remedy the hearing loss. Most

remains primarily a visual learner, in that the child’s full access to language and his/her world is primarily dependent on vision (the child’s strength) and not on the auditory channel (the weakness).

Even though hearing aids and cochlear implants are used to facilitate communication access, they often do not provide for the full and total access to communication that is necessary to assure that one is



**Being deaf does not prevent the child from doing and becoming whatever he or she wishes to do and become.**

hearing aids amplify a range of sounds specific to the individual’s hearing loss. If a person has a loss in the high frequencies, but not in the lower ones, most hearing aids will amplify only the high frequencies. Cochlear implants, conversely, are designed to provide direct stimulation to the auditory nerve. The hearing aid or the cochlear implant can be, for some deaf children, valuable tools for the development of speech. However, it should be understood that even with hearing aids or cochlear implants, the child

socially and linguistically integrated into society. While these tools may enable the child with a hearing impairment to converse with speech quite normally in a one-on-one situation and may even result in the child being well-adjusted socially, in all actuality, he/she may still be deficient when it comes to having a full, accessible language that can be the cornerstone for developing literacy in reading and writing. This is an issue because the teaching approach to which the deaf child is subjected determines the educational and

social success of the child. If the language used in the educational and social environment is not completely accessible, one can only imagine the consequences for the person, both as a student and later as an adult: incomplete access to literacy, a negative impact on the development of self-esteem, and wandering in a no-man's land relative to cultural identification. As such, the hard of hearing child might be termed the "twilight child" - a child who often does not fully fit linguistically or socially into either the Deaf or hearing worlds, and ultimately, often as an adult, must choose which of the two worlds is the most easily accessible for his/her primary social and linguistic interactions.

According to Dr. Jean Andrews, the director of Deaf Education at Lamar University, children who are deaf must go through years of arduous speech training to learn how to

translate the sound sensations of the cochlear implant, and even then there are no guarantees that the cochlear implant will foster language development. Dr. Nancy Niedzielski, a Rice University linguist, states, "Teaching children to interpret the input takes years, and outcomes are extremely varied.... Some [implanted] children never acquire the ability to make sense of the sensation of sound. Meanwhile, they have lost precious time that could have been spent learning to speak, read, and write by using American Sign Language [as the first language of communication and instruction]."

While for some children the cochlear implant has been quite successful in fostering the development of speech and increased auditory capabilities, parents should be aware that the exception should not be interpreted as the rule, and if they adopt the

pathological model, there is no guarantee that their child will grow up to be a "normally" speaking adult or will be amalgamated successfully into the hearing world.

## Concerns of the pathological and socio-cultural models of deafness

Educationally, the pathological model's major concern is with the production of intelligible speech and assisted hearing. The goal of the difference model is the mastering of subject matter content. Inherent in both models is the belief that the child who is deaf should be exposed to and expected to master the same curriculum that is required of hearing children.

Socially, the view of the pathological model is that the child should be

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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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Ella Mae Lentz, Dr. Mervin Garretson and Dr. Clayton Valli, poets and educators. Yet, as needed, the Deaf also embrace segregation, simply for the enhancement of deeper and more meaningful communication and cultural involvement.

integrated into the hearing world. The view of the difference model is that people who are deaf will naturally socialize in both the Deaf and hearing communities. The individual who is deaf is, by necessity, a functioning member of both cultures; one has only to look at the worlds of work, athletics, law, mathematics, engineering, education, and theater: Marlee Matlin, Emmy Award winning actress; Kenny Walker, defensive end for the Denver Broncos; Dr. Robert Davila, university president; Andrew Foster, established schools for deaf children throughout West Africa; William Hoy, played professional baseball for Cincinnati; Douglas Tilden, a famous sculptor whose works adorn the streets of San Francisco; Konstantin Tsiolkovsky, a Russian scientist whose plans helped launch the world into the Space Age; and,

Perhaps the most insidious element within the pathological model is that of paternalism; the basic assumption being that hearing people have an obligation to assist those who are deaf in overcoming their disability. The attitude expressed in the difference model is that those who are hearing should work with, not for, the Deaf towards mutual respect and equality, fully realizing that given equal access and opportunities, the Deaf can succeed on their own. Given an equal education in the least restrictive environment, the deaf child can do anything that a hearing child can do.

Deep and meaningful communication and the development of a socio-cultural identity are of utmost importance in the life of a child who is deaf. Communication involves shared meanings, and without

shared meanings, there is no meaningful language development, and socio-cultural identity is severely impaired. It is vitally important that the deaf child be afforded the human rights of easily accessing language and not becoming a clone of others' expectations. If the parents will take the child's lead regarding communication and language; if the parents will become the child's advocate related to an appropriate education in the least restrictive environment; if the parents will make provisions for the child to be socially and educationally engaged with Deaf children and Deaf adults – their child can and will internalize the wisdom in the words of Dr. I. King Jordan, the former Deaf president of Gallaudet University in Washington, DC: "The deaf can do anything that a hearing person can do, except hear!" ■

*For reader feedback on Part One of this piece, please see page 46.*

**Dr. J. Freeman King** is the director of Deaf Education at Utah State University, and has directed teacher training programs in Deaf Education at the University of Southern Mississippi and at Lamar University. He has worked as a classroom teacher, coach, Dean of Students, and supervising teacher at the New Mexico School for the Deaf and the Louisiana School for the Deaf. He has published numerous articles for professional journals and is the author of two books related to Deaf Education, *Basic American Sign Language Principles for Hearing Parents of Deaf Children* and *Introduction to Deaf Education: A Deaf Perspective*.



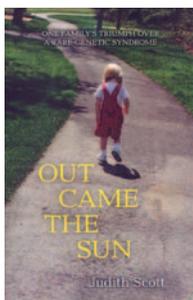
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## Out Came the Sun

By Judith Scott  
Academy Chicago  
Publishers, 2008  
270 pages, \$22.10



After six years of marriage and a failed pregnancy, Judith and Greg Scott welcome their perfect blonde baby girl Emily into the world, only to learn within days that she has a rare heart condition and a blockage in her kidney – among other severe malformations – both of which will warrant immediate corrective surgery. While her tiny body heals, Emily fails to reach significant developmental milestones. Despite the best efforts of her parents and therapists, Emily's gains at six months seem infinitesimal relative to those of babies her age. A diagnosis of Partial Trisomy 13, an extremely rare chromosomal syndrome with "only 50 documented cases", confirms to Judith what she had long suspected but had refused to accept: her baby is severely "disabled".

Therein lays the backdrop of this beautifully-crafted memoir by Judith Scott, who chronicles her journey through the stages of grief, and the emotional and physical toll the experience of raising an exceptional child has on her marriage and ability to function day-to-day. From her

*A new fascination of mine is to study other parents of kids with disabilities to see how they are faring...I am rewarded with tired eyes masquerading behind brave smiles, a courageous resolve alongside devastation. I squirm and am uncomfortable in this environment, and I can't figure out why until I glance over at [my husband] Greg. He has the same eyes, the same steely façade as all the other parents. That must mean I have it, too, and I swallow hard to realize that I am not the onlooker I pretend to be.*

- *Out Came the Sun*

constant need to compare Emily to other children with special needs, to her obsession to push herself to the limit by exercising and acting out juvenile fantasies including getting a belly-button ring, Scott paints a heart-wrenching picture of her anguish, rage, embarrassment, betrayal, distrust, and loss of control that is sure to strike a particular chord among exceptional parents and caregivers.

Yet as its title suggests, *Out Came the Sun* leaves readers with a sense that Emily's future – and that of her family's – is full of promise. For every disclosure of pain and sadness, Scott reveals her increasing admiration for Emily's tenacity in the face of overwhelming odds,

and her commitment to help her daughter defy doctors' declarations that she will "never speak or walk". With time and unwavering support from her husband and friends, Scott begins to heal emotionally, taking pleasure in her daughter, professional pursuits, and a rekindled marriage that opens to the possibility of additional children.

*Out Came the Sun* is a legacy to Scott's family and a testament to her personal voyage from hopelessness to strength and determination. It is a wonderful, uplifting story of faith, reminding us that even the youngest and most "disadvantaged" of people have lessons to share. But most importantly, it is the story of every parent and exceptional child who

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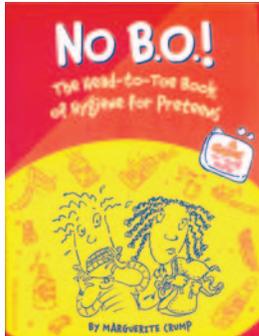
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## No B.O.!

### The Head-to-Toe Book of Hygiene for Preteens

By Marguerite Crump  
Free Spirit Publishing, 2005  
118 pages, \$16.95



by LAUREN SILVER

**B**ad breath, facial hair, problem skin, and the rollercoaster of emotions that accompany them. It's a lot for one preteen to handle, especially when he or she feels shy or uncomfortable about approaching an adult to talk about such physical and emotional changes. In recognition of kids' overwhelming desires to explore puberty-related

issues discretely, teacher and journalist Marguerite Crump created *No B.O.!*, an informative instruction manual for preteens on the ins and

as a reference to ensure that they are covering all important aspects of the body when exploring the subject of hygiene together. Although

*You're at a stage in your life when looks become more important. Some people you know may even seem to obsess about appearances and act like it's their mission in life to make nasty comments about others. They may act superior, but they're not. It's hard to ignore this behavior, but try to anyway. Don't take it too much to heart.*

- No B.O.!

outs of personal hygiene and body maintenance. Having consulted extensively with students and school nurses, Crump covers every topic from head to toe in great detail. Divided into seven chapters ranging in length from 10 to 20 pages, *No B.O.!* emphasizes the importance of proper hygiene and thoroughly details the maintenance demands of each body part – beginning at hair and proceeding with the face, mouth, hands and parts below – all the way to the feet. As the title suggests, there is even a chapter on body odor!

Parents and caregivers of younger children may wish to use this book

designed for “typical” preteens between the ages of 9-13, educators and parents of high-functioning teens or adults with developmental disabilities may find *No B.O.!* helpful when working on the acquisition of daily living skills. Prospective readers should be aware, however, that *No B.O.!* contains some unnecessary details and tends to get a little redundant at times. Moreover, the large amount of text on each page may prove intimidating for some readers to tackle independently.

Crump's injection of humour, cartoon drawings on intermittent pages, and engaging “Fact!” and “Myth” boxes touching upon historic practices and common misconceptions, will undoubtedly keep young readers turning the pages. The inclusion of a clear and coherent table of contents, introduction, bibliography and index facilitate the book's navigation. The author reaches out to readers further by inviting them to contact her personally. Of all the advice she offers in her book, perhaps most valuable is Crump's encouragement of readers to embrace themselves for who they are. Preteens will come away with the reassurance that the changes and accompanying emotions they are experiencing are not only normal, but shared by many of their similarly-aged peers. ■

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*Andrea Cameron and her son Kieran, age 15 months.*

## Finding **My Voice**

by ANDREA CAMERON

**B**efore the birth of my three-year-old son, Kieran, I was mortified by my singing voice. As the person who would lip sync the national anthem at school, even the singing of “Happy Birthday” has always felt interminably long.

On one occasion while attending a prenatal yoga class during my second trimester, I learned that African women compose personal lullabies to sing to their babies throughout pregnancy, birthing and childhood. Thinking this was a lovely idea, I tried singing to Kieran when he was in my womb but my voice

betrayed me. Convinced that no child would want to be born to a mother who croaked her way through the simplest of lullabies, I decided it was best to stop.

Kieran’s birth was difficult. Born by emergency C-section, my baby began having unexplained seizures when he was just two days old. The first seizure occurred after his first bath while we were still in the hospital. My husband and I froze as we watched Kieran’s right arm and foot jerk while his eyes deviated. Although we really didn’t understand what was happening at the time, we both had an ominous feeling that something was terribly

wrong. Over the next three days, Kieran had several more seizures. He spent his next five days of life under observation in neonatal intensive care.

While our family was compassionately attended to by hospital staff, it was difficult for my husband and me to bond with Kieran when our every move was monitored. I was admonished not to let him sleep at the breast (apparently a negative nursing habit) and upon leaving briefly for a dinner break, he was given a pacifier without my consent. While this was a minor concern given everything we were experiencing, it was something I hadn’t planned on doing.

I recognized that everyone around me had the best of intentions; I simply felt as though I had no control over my own child. Despite the terror that the seizures would return, I wanted nothing more than to take my baby home to experience all of my inevitable parenting mistakes and triumphs in private. As I watched other mothers in the NICU sing to their tiny babies, I wanted to sing to Kieran as well but I was too self-conscious.

The hospital discharged Kieran when he was 10 days old, explaining that we needed to take a wait-and-see approach. Since he had not seized in several days, no medication was prescribed. Once at home, my husband and I struggled as first-time parents. Kieran's cry was sudden, loud, and so high-pitched that we would panic trying to soothe him. I felt like a failure. My plans to have a natural, unmedicated birth had been replaced with every medical intervention imaginable – C-section, epidural, Demerol – the very things I had hoped I wouldn't require.

Breastfeeding was a priority for me but the day we returned home from the hospital, Kieran refused the breast. His tiny fists clenched under his chin and he screamed whenever I tried to nurse. This was especially frustrating because it was the one thing that had consis-

tently been going well since his birth. I used a breast-pump and bottle-fed Kieran for two weeks until one day he returned to breastfeeding instinctively.

My voice was shaky and uncertain but Kieran responded immediately. I still wonder whether it was comfort or shock that made him stop crying, but it didn't matter;



Andrea and Kieran at 27 months, at PEI's Tracadie Bay.

One night, I was home alone with my inconsolable son. When his cries became so unbearable I had to plug my ears and leave the room to catch my breath, I decided to sing to him. The only problem was that I couldn't remember any songs; the lyrics to the standard lullabies left me as I held my shrieking baby. Ironically, even though it was May, the first song that came into my head was *Silent Night*. I began to sing.

I discovered my voice – and a few moments of peace.

From that moment on, I began to sing to Kieran all the time. Over the years, my repertoire has grown to include *Amazing Grace*, *Redemption Song* and *Wheels on the Bus*. I no longer care who hears me.

My son's love of music has carried us through some difficult times. Kieran's early seizures were a sign of a more complicated neurological problem. When he was diagnosed with epileptic spasms – a serious form of childhood epilepsy – at five months old, we had to put our young baby on several anti-epileptic drugs in an attempt to control his hundreds of daily seizures. While these medications can be very effective in controlling seizures for many children, they didn't work for Kieran. Even when he was on three

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different medications at once, the spasms did not decrease. The drugs' side effects were terrible. Kieran became lethargic and lost his muscle tone. There were times he was so sedated that he couldn't even eat because he didn't have the strength.

Ultimately, the toxic levels of drugs in his tiny body caused his muscles to weaken and Kieran developed aspiration pneumonia which necessitated hospitalization. It was then that my husband and I decided to take more personal control of his treatment. I began to follow my instincts and employed a more holistic approach. We made some controversial decisions but our son became spasm-free in a short time. In that time, we weaned his medications and he began to exhibit significant developmental strides - sitting independently, crawling, and even saying "Mama".

One evening, after 10 spasm-free months, strange breathing sounds coming from Kieran's baby monitor prompted me to go check on him. I entered his room to find my son having a grand mal seizure. By the time we were in the ambulance en route to the hospital, he had been seizing for at least 15 minutes. As I watched his small, convulsing body on the stretcher, I started singing *Twinkle, Twinkle, Little Star*. I sang as if my voice was the only thing that could bring him back. Kieran had to be sedated to make his convulsions stop and, after such a long seizure, he was exhausted and sore. We were told that he'd experienced an atypical febrile seizure - that a viral fever had likely been the cause. I sat at his bedside all night waiting for the reassurance of his voice, his smile. Each time he whimpered or stirred, I sang until he was comforted. At dawn, he opened his swollen eyes.

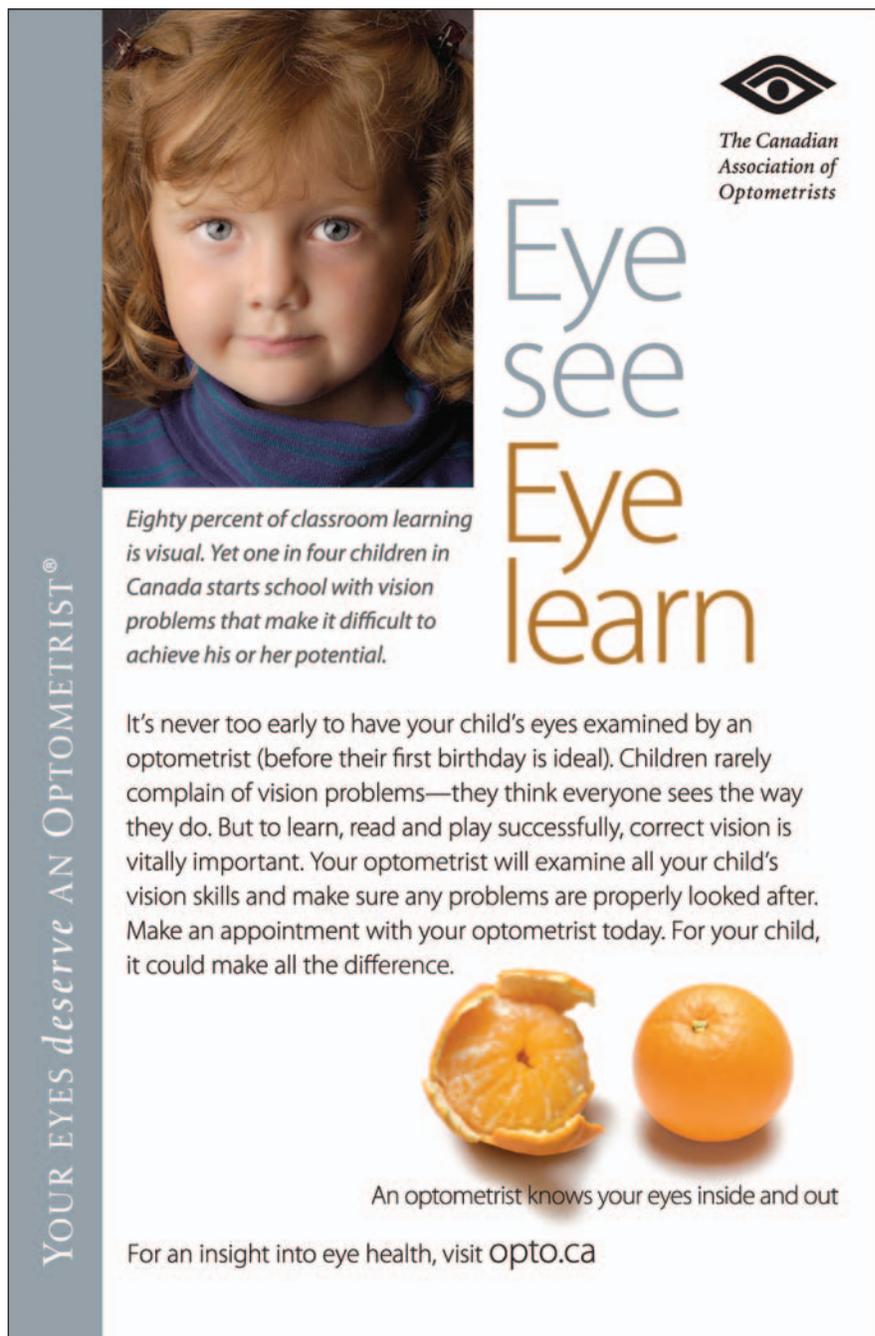
"Ball?" he said.

I cried, releasing a flurry of contradictory emotions: joy, anger, fear, relief. I held Kieran just for a moment. Then, I frantically started looking for his favourite ball in the diaper bag.

One year after this painful episode, Kieran has, to our cautious relief, remained seizure free.

Finding my voice is about more than singing; it's about mothering a son with challenging needs. It's about learning to ask the right questions. It's about finding the best possible care for Kieran. It's about being his advocate.

My voice reassures him; my voice calms him; my voice speaks for him. And so, even if I'm a little off key at times, I'll keep singing us through this long journey. ■



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# Inspiration

A tribute to people who have achieved  
in spite of remarkable challenges

*I have always been a dreamer; I will always be a dreamer. I have discovered that The Power of the Dream gives hope, strength, courage, empowerment, and brings about profound transformation in individuals and groups of people, if one simple rule is followed - honour the dream by taking action.*



## Terry Kelly

Singer-songwriter, motivational speaker, double silver medallist at the 1979 Canadian Track Championships, former member of the Canadian Track Team that competed in the 1980 Paralympics, person who is blind, father, nominated for four Canadian Country Music Awards and a JUNO, winner of seven East Coast Music Awards, released the first commercially-produced music CD in the world that includes Braille on the liner notes, documentary filmmaker, winner of the 2005 Canadian Country Music Association (CCMA)'s Humanitarian Award, two-time Honourary Doctorate recipient, Member of the Order of Canada



# Ask the Expert

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

## When Self-consciousness Cuts into Summer Fun

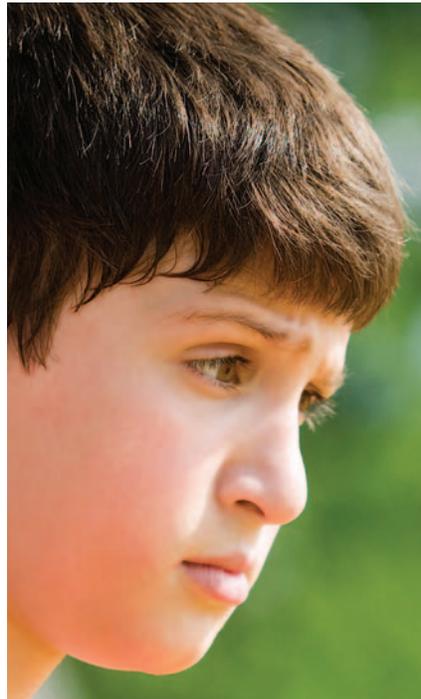


PHOTO: JULIAN HABER

**Q** My ten-year-old son Amir was born with a mild hearing impairment and has been wearing a behind-the-ear (BTE) hearing aid

since he was four. Amir attends a regular school and has had the same classmates since preschool, who take his hearing aid for granted and have always embraced him as part of the group. The fact that Amir also happens to be a fabulous artist and is known as the fastest runner in the class also doesn't seem to hurt his popularity, but I would like to believe that he would have gained their acceptance regardless.

I've noticed that as he matures, Amir is becoming increasingly self-conscious about his hearing aid. Two years ago he began growing his hair long so that it covers his ears, and last summer he refused to participate in his day camp's daily free-swim activity because doing so would have meant removing his hearing aid for everyone to see. Instead, he spent each hour-long timeslot on the grass, flipping through a comic book in the intense heat. His pat line in response to campers' curiosity around his lack of participation was that he "hates swimming" – which couldn't be farther from the truth.



Amir will be returning to the same camp this year. While I always remind him that there is nothing to be ashamed of and advised him that many returning campers may

likely already be aware of his hearing aid, he is dead set on maintaining his "secret." It saddens me to think that Amir will spend another summer poolside. I wonder if there is anything I might be able to do to help him to gain some perspective about his disability.

**A** As a normal part of development, kids commonly make comparisons between themselves and others as a means of building a realistic sense of their relative strengths and weaknesses. Imagine what the world would be like if each of us grew up to believe that we were the epitome of perfection!

In Amir's case, having a disability that is actually evident to his peers has taken these comparisons to a heightened level of concern for him, getting in the way of his functioning by inhibiting the choices that he makes.

### Help make a difference!

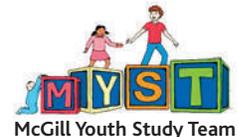
The **McGill Youth Study Team** is a specialized group of educational researchers committed to the study of attention and problem solving among persons with autism spectrum disorders, Down syndrome, and other genetic syndromes. We are looking for children (5 years and older), adolescents and young adults to participate in our studies that include computer and problem solving games. Small gifts are provided to all participants.

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You describe Amir as an all-around boy with many well-developed skills – social, creative and athletic. Yet, somehow his disability has begun to dominate his self-perception, overshadowing these attributes. You are

rightfully concerned about needing to find some more effective means of helping Amir to respond to his hearing impairment than what you have already tried, not only because of its current toll but because, if left

unchecked, Amir's self-consciousness will likely be further exacerbated with adolescence.

Let us consider first that Amir appears to have developed these insecurities over time since you mention that he began growing his hair long enough to cover his ears a couple of years ago. A variable such as a child's choice of hairstyle can be tricky. On the one hand it appears to be a benign expression of the child's personal taste, and as a parent you would have wanted to endorse this expression of autonomy. On the other hand, being complicit with Amir's wish for long hair may have been (and continue to be) perceived by him as supporting his wish to hide his disability.

Unfortunately, once Amir's refusal to participate in swim last summer was tolerated, this may have further reinforced his belief that his condition is shameful since he was in effect given permission to sit on the sidelines.

Children largely develop their sense of "self" from the cues that parents provide, so while it is clear that on one level you have been normalizing Amir's experience and thus helping him to maximize his capabilities, it may also be possible that he has picked up on your own sense of shame or discomfort – feelings so subtle as to be out of your awareness.

Of course, we cannot turn back the clock and my speculations are not designed to cast blame but rather to invite you to get in touch with your deepest feelings about Amir's disability and whether there has been an ongoing, unconscious collusion with him to maintain secrecy.

Before you can effectively help Amir to gain perspective about his

 An advertisement for the Autism Awareness Centre inc. It features a close-up photograph of a young girl with brown hair and a red shirt on the left side. The background is a light blue and green pattern. The text on the right side reads:
 

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## Ask the Expert

disability you will need to be mindful of the possibility of transmitting mixed messages to him and to be sure that from now on they are free of ambiguity. Once you come to terms with your own feelings and truly believe that Amir is alright, then so will he.

You will then be ready to effect a two-step process, in which both steps work in tandem in response to

The second is to draw a distinction for Amir (and for yourself) between what is expected and how he feels. It is quite possible that it will come as a relief to him to have normal expectations conveyed and his power of dissent removed. (What child really wants to sit poolside on a hot summer day guarding a secret?) It is also predictable, however, that Amir will express anger at being “forced” to comply.

### Amir’s feelings need to be given expression. Your role is to foster a sense of safety for Amir to put his feelings into words instead of acting them out.

Amir’s refusal to go swimming, or in similar situations. The first is to be clear and unequivocal in your expectations as a parent. Confirm for yourself that your expectation is an appropriate and fair one. Then state it simply: “This summer you will be participating in swim.” If Amir thinks you are wavering it will impact on his ability to accept your position.

While your expectations are not negotiable\*, Amir’s feelings need to be given expression. Your role is to foster a sense of safety for Amir to put his feelings into words instead of acting them out. This is best accomplished by being a good listener and validating his feelings rather than attempting to disprove their legitimacy.

\* While I generally advocate that parents be open to negotiation and maintain flexibility enough to change their minds under certain conditions, my point in this case is to eliminate uncertainty for the child.

A full discussion with Amir, which would take place over time, would include the possibility of considering with him ideas that are both practical and philosophical as a means of helping him work through his conflicted feelings about his condition and bringing him to greater self-acceptance.

You might discuss, for example, whether Amir is ever teased by peers and if so, what responses are more or less effective. Help him draw the correlation between his own comfort level with his condition and the way in which others respond to him and to consider in particular the effects of his self-marginalization. Help him, as well, to restore his confidence by acknowledging his many strengths and talents so that he can attribute less significance to his disability. Explore with Amir his thoughts about secrets and what people gain or lose by keeping them, and encourage him to speculate about the acceptance of difference, since all people have limitations, some more evident than others.

Here’s hoping that Amir’s summer is filled with all of the fun that a 10-year-old deserves! ■

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



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**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 OPTSQ. She is a teacher and supervisor at the Argyle Institute of Human Relations in Montreal.

# TICKET TO RIDE

Tips to prepare  
your child  
to navigate  
the public  
transit system

by SARAH KEENAN



The ability to travel independently via public transportation is a significant step in the transition from adolescence to adulthood. Whereas busy parents may embrace the milestone as an end to years of chauffeuring their children around town, teens view their new ability to hop on a bus or subway as a symbol of their increased emancipation. With limited or no access to wheels of their own, the ability to navigate local transit systems is integral to teens' social development; enabling them to meet up with friends or go out spontaneously on the weekend, for example. For many, this capability may also be key to a successful coop placement in high school, holding down a part-time job, volunteering, or attending academic or vocational post-secondary programs.

For youth with sensory, intellectual or physical disabilities, however, using

public transit can often be quite daunting and anxiety-provoking. Anyone who has taken a bus in a foreign city can likely relate to the challenges of finding their way through an unfamiliar transit system. Transit systems have their own sets of rules, procedures and norms that must be learned, remembered and performed. There are myriad factors to consider prior to boarding a bus or subway – factors that many of us take for granted. For instance, how do you know which bus to board? How much is bus fare? Can you pay the fare with cash or must you buy a ticket? Where are tickets purchased? Where do you put the ticket upon boarding the bus?

In addition to these issues, people with disabilities may face further challenges. Individuals with intellectual disabilities, for example, may need explicit guidance and educa-

tion around the social rules of public transportation: Where is the safest place to sit? When is it appropriate to speak with strangers? How do you keep yourself and your money safe? How would you find help if you needed it? What would you do if the bus or subway broke down? By the same token, individuals with physical disabilities who rely on mobility devices to get around may need to research which buses and subways are accessible well in advance of their departures.

As a Life Skills Coach in the Skills for Transition program at Toronto's Bloorview Kids Rehab, my role is to help foster exceptional teens' confidence and encourage them to solve problems, take risks, make mistakes, and learn from those mistakes in a supportive and non-judgemental atmosphere with the aim of empowering them to reach new heights.

## TICKET TO RIDE

Created by Bloorview's Life Skills and Wellness Institute for youth ages 15-21 with physical, sensory and intellectual disabilities, the Skills for Transition program strives to increase participants' self-determination and community integration by helping them to develop the fundamental life skills necessary to function as independent adults. Such skills include the ability to problem-solve, make decisions, manage their day-to-day responsibilities,

wheelchair), accessibility features of subways and buses and their stations, what to do in the event of a problem, and how to select an appropriate travel route from starting point to destination. Teens will ultimately be challenged to travel independently (with a staff member shadowing them for safety) to a destination of their choice. Youth will be responsible for all the planning involved, including how much time they will need to allocate for their travel, any

Families don't need access to a Life Skills Coach to begin working toward the transition to adulthood, and more particularly, independent travel on public transit. Recognizing that every person has a unique set of strengths, skills and challenges, some youth will be able to travel safely on public transit independently, while others may always need some level of support. The latter may still benefit from becoming more familiar with their local transit systems; training teens in this area will not only enable them to feel more at ease with the process in general, it will also encourage them to become actively involved in making decisions around activities that they participate in. Perhaps most importantly, it will help them to learn important safety rules and appropriate social etiquette – crucial life skills which will undoubtedly come in handy as they mature.

### There are a number of things you can do to help prepare your son or daughter for independent or supported travel on public transit.

and to set and master specific goals. Over the years I have found that among the many goals my clients and their families hope to achieve, almost all of them cite the "ability to take public transportation independently" as a priority.

In response to clients' overwhelming desires to accomplish this particular goal, Skills for Transition will collaborate with the City of Toronto Department of Parks and Recreation this August for the second consecutive year to offer "Summer in the City", an eight-day workshop that progressively introduces participants to the transportation services and routes offered by the Toronto Transit Commission (TTC). Held at a local community centre, the program combines in-class instruction with lots of hands-on, practical experience. Over the course of the training, Life Skills Coaches will cover such topics as community safety, the etiquette and social rules of public transportation (for example, standing to the right on escalators, allowing people to exit trains before getting on, and where to sit if you are using a mobility device such as a walker or

supplies they might require including money, and, of course, plotting the route there and back.

Participants of last summer's pilot program embraced the opportunity to set personally meaningful goals and took on their final challenge with enthusiasm. By the end of the eight days, all of the teens had successfully travelled all across the city, and some had even ventured into neighbouring transit systems. Two of the 10 participants had exceeded their personal goals and were travelling to and from the program independently each day. This was something truly inspiring to see.

Keeping in mind the individual needs of your child as well as the realities of your local transit system, there are a number of things you can do to help prepare your son or daughter for independent or supported travel on public transit:

1. When planning trips on public transit, include your child in the process whenever possible. Allow her to take the lead occasionally, as appropriate. For example, ask,

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

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“Which bus should we take to get to our house?” rather than automatically leading the way. In addition to assisting your child to become more familiar with her surroundings and decreasing her likelihood of getting lost, the exercise will strengthen your child’s planning and decision-making skills. Moreover, actively participating in the process will increase her confidence and help her to prepare for the time when she may be entrusted to plan an entire trip independently.

2. Use public transit together as a family, to get to and from appointments, for example. As your child’s parent or caregiver, he associates you with feelings of security and comfort; by taking public transit with your child, you will convey that it’s a safe mode of travel.
3. Point out safety features as you are travelling together, including whom to seek out for assistance.

Develop a safety plan. This might constitute an instruction to call home or to seek the help of a person in uniform if your child is lost or in distress.

4. Familiarize your child with accessibility features. For example, which subway stations have elevators? How might you tell if a bus route is wheelchair accessible? Large transit systems have route maps available to pick up or download. Some systems also have hotlines that offer route and access information.
5. Help your child to resolve problems creatively. Discuss potential challenges that may arise and allow her to suggest possible solutions. For example, if a subway system’s elevator were broken, what would she do? How would she determine whether the following stop has a working elevator? What would she do if she boarded the wrong bus?

6. Allow your child to experiment and make mistakes in your presence. Attempting to figure out how to get back on the eastbound train when the two of you accidentally hopped on a southbound one will be much less frightening for him when you are present and will give him the confidence to solve similar challenges should he ultimately travel alone. Acknowledge mistakes as learning opportunities and celebrate your child’s successes!

7. Set goals that are appropriate for your child and raise the bar as each is achieved. For example, an initial goal for a teen might be to make her way home alone by foot from the bus stop. To prepare for this step, review safety strategies for crossing the street and talking to strangers. Should she safely accomplish this, the next goal might be for her to take the bus alone from the subway station and proceed to walk home once she disembarks. To prepare for this stage, travel the route together with your child multiple times beforehand, so that your teen knows where to get off the bus.

8. Start early. The earlier young people start planning for the future and acquire the skills necessary to lead fulfilling lives, the easier their transitions to adulthood will be. ■

*For more information about Life Skills Coaching or the “Summer in the City” program, call (416) 425-6220 ext 3297 or email [skeenan@bloorview.ca](mailto:skeenan@bloorview.ca).*

**Sarah Keenan** is a Life Skills Coach at Bloorview Kids Rehab in Toronto.

# Insights

A compilation of upcoming conferences and training sessions of interest

## June 16 & 17

**Abe Gold Learning and Research Centre**

### Prevention Intervention: Techniques to Help Manage Crises

*Learn how to care for people who are anxious, challenging, aggressive or out of control using therapeutic techniques, and how to re-establish a rapport with an individual after a crisis.*  
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9am-4:30pm. 8160 Royden Road, T.M.R., QC. Info: (514) 345-8330 x319, info@goldlearningcentre.com or www.goldlearningcentre.com

## July 6-17

**Abe Gold Learning and Research Centre**

### ABA Bilingual Training

*This certificate program will help you to develop the appropriate skills to work with people with autism and other developmental disabilities under an ABA-certified supervisor.*  
Professionals: \$1000 Students/Parents/Persons with ASD: \$600.  
9am-4pm. 8160 Royden Road, T.M.R., QC. Info: (514) 345-8330 x319, info@goldlearningcentre.com or www.goldlearningcentre.com

## August 24-27

**Geneva Centre for Autism Summer Training Institute 2009**

### Understand Me, Motivate Me, Teach Me: Reaching All Students with an Autism Spectrum Disorder

*Sessions include "Simple Strategies That Work for Students with Asperger Syndrome, Autism and Related Disabilities" by Brenda Smith*

*Myles and Diane Adreon.* Fee for 4 days: \$600, 1 day: \$180. 9am-3:30pm. Toronto, Ottawa, Barrie, London, ON. Info: (416) 322-7877, traininginstitute@autism.net or www.autism.net.

## August 25 & 26

**Renfrew Educational Services**

### Workshops on the topic of Autism Spectrum Disorder

*Carol Gray, President, The Gray Center for Social Learning and Understanding, will present two workshops for parents and professionals working on behalf of people with ASD. Topics will include*

*"Friendship, Bullying, & People with Autism Spectrum Disorders" and "Social Stories™ 10.1".* 2050 21 St. NE, Calgary, AB. Info: Sheila Thompson @ (403) 291.5038 x1204 or Sheila\_Thompson@renfreweducation.org.

### EF welcomes your Insights!

To publicize an upcoming conference or training session of interest **FREE** of charge, contact us at [feedback@exceptionalfamily.ca](mailto:feedback@exceptionalfamily.ca). Information will be subject to the discretion of the editor and publisher.

#### LETTER TO THE EDITOR: "A CANADIAN PERSPECTIVE"

Re: Hearing Parents and the Child who is Deaf (Volume 4 No. 3):

In my opinion, the article misinforms families of children with hearing loss on present-day outcomes and choices for Deaf and hard of hearing children. The list of organizations shared by author, J. Freeman King, are either based in the U.S. or are sign-language biased.

Canadian-based VOICE for Hearing Impaired Children teaches deaf children to listen and speak – YES, deaf children can learn to listen and speak – through the advancements of technology deaf children learn to speak where historically they used sign language. The outcomes of our program are the proof of our success with over 100% of our program alumni graduating high school and greater than 50% holding a post-secondary degree.

I believe it is important for your readership to see what is occurring in progressive communities of Canada as a result of early identification of hearing loss and access to enabling technologies so that they can be informed of a Canadian organization that supports an oral communication option.

Deaf children today can become fully included participating members of a hearing society thanks to radical advancements in hearing technology.

Sincerely,  
Norah-Lynn McIntyre  
Executive Director  
VOICE for Hearing Impaired Children  
[www.voicefordeafkids.com](http://www.voicefordeafkids.com)



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Talk to your children about  
rail crossing safety.

You've probably talked to your children about how to safely cross the street.  
But what about rail crossing safety? Do you know all the dangers?

## Rail safety tips

- Remember trains cannot stop quickly.
- Listen for warning bells and train whistles.
- Look both ways before crossing tracks.
- If one train passes, make sure that another train is not approaching on another track.
- Always walk your bike across the tracks.
- Never walk or play on tracks. It's dangerous.

To learn more, visit

[www.cn.ca/safecrossing](http://www.cn.ca/safecrossing)

