

CANADA'S RESOURCE MAGAZINE FOR PARENTS OF EXCEPTIONAL CHILDREN

EXCEPTIONAL FAMILY

Vol. 3 No. 1
Fall 2007

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journey to Shanghai

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PUBLISHER'S NOTE



A year of growth

This past year has seen a number of remarkable new developments at *Exceptional Family*. From the launch of our website and the acquisition of our new Marketing Manager, Julie Klucinskas, to the magazine's overall growth and nationwide exposure, we are proud of the gains we have made since we started out as a fledgling publication in the fall of 2005. Most recently, we have had the thrill of seeing *Exceptional Family* displayed on newsstands and bookstore shelves across the country – a dream that was made possible thanks to Magazines Canada, Canada's leading professional magazine industry association and the courageous independent retailers who believe in our cause. Our gratitude extends to all of them and once again to you – our loyal readers, subscribers and advertisers. Thanks to your unwavering support, we can continue to look forward to many wonderful new growth opportunities in the year ahead.



Warren Greenstone
Executive Director, Miriam Foundation

FROM THE EDITOR



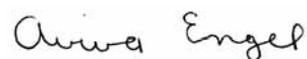
At the risk of sounding cliché

The addition of a second candle on *Exceptional Family*'s figurative birthday cake coincides with another exciting new addition to the EF team; that of our new Editorial Advisory Board. In our ongoing pursuit to raise the high-quality editorial standards established from day one, members of the Editorial Advisory Board will lend their expertise as mentors and stewards committed to protecting the integrity of *Exceptional Family* magazine. We are both honoured and elated not only to have their active participation, but to have earned their "seal of approval."

Contributors with whom I've had the pleasure of working know that I object to the use of clichés – a cardinal journalism transgression. Rather than employ a cliché to express my appreciation to the entire EF team, I will simply say "Thank you." Thank you to our columnists, our graphic designers, our contributors and our advisors past and present. Your tireless efforts and devotion to the magazine's success are what make this publication so special.

Exceptional Family is, after all, only as great as the sum of its parts. (Oops.)

Here's to another great year!



Aviva Engel

EXCEPTIONAL FAMILY

Vol. 3 No. 1 Fall 2007

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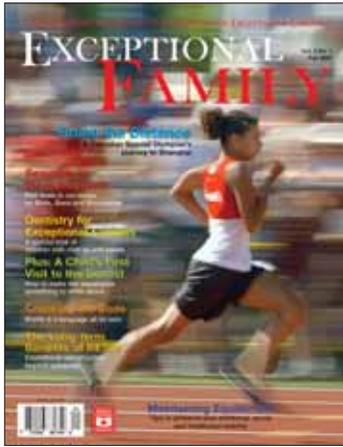
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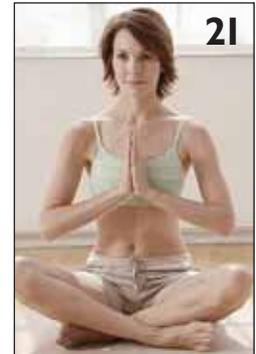
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A compilation of upcoming conferences
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EXCEPTIONAL FEEDBACK

As we celebrate EF's second anniversary, we are delighted to share samples of feedback we have received since the magazine's launch. Our thanks go out to all of you who have taken the time to call, write and e-mail. As always, we welcome your continued input. Drop us a line at feedback@exceptionalfamily.ca

I recently came across your magazine Exceptional Family, and I am very intrigued. As the mother of four children, two of which have Autism, it was refreshing to see a Canadian magazine geared towards parents of children with special needs. Thank you for allowing our voices to be heard.

Amanda Bedard, Southwestern Ontario

Congratulations on your publication. It is replete with interesting information and articles. The format is appealing and professional.

Sheva Strolovitch, Westmount, QC

We were awed by the superior quality of the layout and the writing of all of the contributors.

Phyllis and Ervin Spinner, Côte St. Luc, QC

I work in the public school system with autistic children and love your articles.

Jill LeBlanc-Pastuck, Atlantic Canada

Way to go! The magazine is one of the rare things that I read cover-to-cover. I'm often up very late on nights that we receive each edition – because I just can't put it down. From the human interest stories to every single advertisement, each bit is of interest to me and enlightens me in some way. Congratulations to you and your crew.

Dr. Renee Wolansky, Montreal, QC

Congratulations. The result reflects the hard work and dedication that must have been expended on your magazine and website. Your magazine is elegant, professional and useful. I plan to refer parents to it and your website.

Ruth Feder, Montreal, QC

I must say that your publication is quite an "Exceptional" one! Your magazine approaches every issue with a sense of compassion, caring and a true desire to provide information in the most sensitive and competent manner possible. For that, I applaud you. I am proud to say that I have been reading since the first issue.

Dr. Dovid Berkowitz, Rockland County, NY

I really appreciate the content of the articles, the variety of topics related to exceptional children as well as the layout of the magazine. I think it is a great idea to have developed this publication which was long overdue!

Sheila Segal, Montreal, QC

Your magazine is first class.

David Stephenson, Chambly QC

I wish to say a HUGE thanks – the first time I read your publication I was thrilled to see a Canadian resource for families of exceptional children. Wow! We subscribed right away. I wish to thank you – most heartily!

Alison and Peter Macdonald, Kingston, NS

I have found your magazine to be an excellent source of information as well as an inspiration by the many stories of hope that it relates.

V. Silver, Montreal, QC

I shared issues of Exceptional Family with parents I know and even some neighbours that have children with special needs. The majority of those I spoke with found the magazine interesting and were pleased to finally see a Canadian product instead of American.

Debra Saxe-Melillo, Etobicoke, ON

We enjoy reading your publication and find it very informative.

Joanne Black, Pointe Claire, QC

After reading Exceptional Family magazine, I was touched by the informative yet heart-warming articles.

Sharon Taylor-Ducharme, Montreal, QC

I had the pleasure of reading your magazine and I was pleasantly surprised by the quality of the articles.

Claire Tranquille, Montreal, QC

As the mother of a teen with autism, I'm thrilled to see a magazine that explores issues faced by so many families.

Amy Baskin, author, More than a Mom: Living a Full and Balanced Life When Your Child has Special Needs, Guelph ON

Keep up the good work...there is a need for this type of magazine.

Linda Stuart, Winnipeg, MA

Your magazine is an excellent resource.

Marion Ziolkoski, Saskatoon, SK

Your magazine is really amazing. It impresses everyone I show it to. I am so happy that you have created a magazine about exceptional families and people. It is nice to see such a professional, honest, useful resource available across Canada.

Renee Figlarz, Dyslexiability Inc., Westmount, QC

I thoroughly enjoy reading your wonderful magazine. It is informative and necessary. I always eagerly await each edition and I would like to congratulate you on putting together such a wonderful publication.

Lainie Smajovits, Montreal, QC

We are thrilled at the publication of a Canadian magazine celebrating inclusion in our communities, schools and the workforce. Exceptional Family will surely prove to be an extremely useful resource not only for families, but the general public as well. Again, we at the CDSS applaud your efforts. You are helping to create a society where inclusion is the norm, people with disabilities are celebrated and citizenship as a whole benefits!

Lindsay Heintz, Canadian Down Syndrome Society, Calgary, AB

Your magazine is a wonderful "Inspiration" to exceptional families everywhere.

Beverly Cammy, Town of Mount Royal, QC

Just a short note to compliment and thank you on your article in Vol. 2 Winter 06 called "Blind City." As a visually-impaired person, it was a delight to read about O Noir Restaurant and to learn about "the blind leading the blind." It's all about "walking in someone else's shoes" and it was enlightening to those who "just don't get it!" Bravo to you, who always write honestly and are informative. Keep up the good work.

Sandy Back, Saint-Laurent, QC



GOING THE DISTANCE...

A Canadian Special Olympian's Journey to Shanghai

by LISA TABACHNICK HOTTA

In many ways, 19-year-old Reisha Baxter of Brantford, Ontario is just like any other teenager; she likes to hang out with her friends, attend school dances, play sports and tease her younger brother Steven. However, beyond her tall athletic frame which makes this pretty girl stand out among her peers, Reisha also lives with a number of significant physical and intellectual disabilities including hemangioma¹, a heart defect serious enough to require open heart surgery when she was a toddler, partial blindness and deafness and a moderate intellectual delay.

Adopted along with her brother by Ted and Susan Baxter when she was four years old, Reisha also endured facial reconstruction surgery to her lips and the orbital area of her eye to repair the parts of her face impacted



Reisha and her brother Steve proudly display the medals she earned at the 2006 National Games in Brandon, Manitoba

by the hemangioma. "When she was younger, we wondered why she bumped into things [before it was discovered that she was blind in one eye]," said Ted. "At about a month old, the hemangioma covered her face and lips and she had to endure injections through the eye...the mass put pressure on a lot of areas on her face and there was nerve damage."

Today, any sign of facial disfigurement is minimal. Because of her intellectual disability, certain tasks that involve cognitive reasoning such as counting and using money, cooking, following directions and taking phone messages pose a challenge for Reisha. "Often Reisha knows exactly what she wants to say, but can't express it or quite get it out. With a little prompting and a few questions, she can come up with the right information," said Ted.

One might think that the long list of disabilities attributed to Reisha would restrict her day-to-day functioning. It soon becomes apparent upon meeting the star athlete, however, that her strong will and determination perpetually remain intact, regardless of any obstacles that may stand in her way. At her school in Brantford, for instance, Reisha has succeeded in forming meaningful relationships

¹ A hemangioma is a congenital benign build-up of blood vessels in the skin or internal organs. Hemangiomas of the eyelid may interfere with the development of normal vision and must be treated in the first few months of life. On rare occasions, the size and location of hemangiomas may interfere with breathing, feeding, or other vital functions. These lesions also require early treatment.



with friends and acquiring many new skills. “I learned how to cook and I’m taking horticulture,” Reisha said. “Cooking is my favorite, because we can taste some good food.” When she’s not learning her way around a kitchen or garden, Reisha surfs the internet, works on crossword puzzles and, with the support of a social worker, volunteers at both the SPCA and at a local daycare centre. As her father proudly reflected, “Reisha’s always adapted to her disability. Reisha acts just like any regular 19-year-old.”

Confidence in herself combined with a natural athletic ability and the support of doctors, social workers, friends and family have worked wonders for Reisha; so much so that her amazing talents and vivacious personality shine instantaneously while any limitations seem to fade into the background.

A Star is Born

Reisha’s most noteworthy distinction, however, is her ability to run faster than much of the Canadian population, competing (and winning) in many races. To date, Reisha has 86 first-place ribbons from Special Olympics track and field and swimming events; the majority of which stem from her participation in track competitions. Within the track and field genre, the 100 and 200-metre races are her specialty.

In addition to successfully qualifying at the necessary local, regional, provincial and national Special Olympics Games, Reisha was recently asked to represent Canada at the upcoming Special Olympics World Summer Games in Shanghai along with 82 other Canadian Special Olympics athletes. The Games will take place from October 2 to 11.



Reisha and her parents, Ted and Susan Baxter

Reisha’s most noteworthy distinction, however, is her ability to run faster than much of the Canadian population, competing (and winning) in many races.

Originally participating in soccer through Special Olympics, Reisha was “scouted” by a track and field coach who spotted her out on the field when she 13. The coach asked the Baxter family if Reisha might try track and, impressed by Reisha’s natural speed and ability, he encouraged Reisha to make the switch from soccer to track and field full-time. After cheerfully tagging along to her brother’s various sporting events and tournaments for many years, Reisha’s recent success in Special Olympics gives her a “chance to shine,” her mother Susan noted.



Even when the weather hits 34°C, Reisha works tirelessly on her form. Pictured here, Reisha practices during a track training session at Lions Park Track in Brantford, Ontario in August.

Now in full competition mode and training for the 2007 Special Olympics World Summer Games, Reisha practices more than three evenings per week with both a Brantford club and with her Special Olympics team. While one might wonder whether all of her hard work and constant training begins to wear her down after a while, Reisha claims that she wouldn’t even mind if her training hours were increased. “I would love to be training a lot. I keep on going. I don’t get tired,” she said cheerfully.

A long-time coach for Special Olympics Canada (SOC) and for Reisha, Brittany Brown highlighted the star athlete’s prowess and achievement: “She’s changed in many ways – her time has improved drastically – in the 100 metre race [her best time has changed] from 17 seconds to 14 seconds over the last



Reisha doing an incline bench press with personal trainer Carrie Chan

two years. On a personal level, Reisha has built a lot of friendships during her travels and a personal connection to her fellow athletes. She really is an amazing person," said Brown. Reisha's feelings for her coach are mutual. "Brittany is fun and she's great to hang out with," she said with a smile.

The World on Their Shoulders

A compelling sentiment is shared by Reisha's parents, her coaches and SOC staff: Special Olympics athletes have so much to teach the "differently-abled" population. Cheering for team-mates, respecting oneself and others, maintaining a positive attitude; all of these noteworthy characteristics are often found in Special Olympics athletes.

Reflecting upon the entire SOC team, Brown emphasizes that whether they're winning or losing, most exceptional athletes excel in the skill of good sportsmanship. "They're really not different [from other athletes]. [The special athletes] have a general interest in and love of life. They don't play mind games and they all just accept each

other. They don't care that someone's faster or better. I don't see that in the working world or at school. [These athletes] don't make assumptions about people. I think they recognize that they're different so they accept other people's differences," observed Brown.

Marian Coulson is the Director of Sport for Special Olympics Canada. She first met Reisha in 2002. "Reisha was young and she stood out because she was a very



Reisha doing leg-stretching warmups with fellow runners Nathan Purdy (left), and David Hutcheon (right), from Brantford Special Olympics

good athlete," said Coulson. "She is competitive in a very positive way because [she and her fellow athletes] support each other. Reisha makes sure everyone's included. She's really mature and has a positive outlook on sport and competition."

With all this praise from coaches, friends and family, who does Reisha most admire? "My parents are my heroes," she said. "They cheer me on when I go to the track meets and I'm always very happy when they're there." Ted and Susan certainly reciprocate their daughter's sentiment and say they have benefited greatly from Reisha's involvement with Special Olympics. "We have a daylong track meet in Brantford once a year organized by Brittany

Brown and her mother, Debbie," explained Ted. Participants come from other cities to participate and the group holds a large parade afterwards. "I wouldn't miss it for anything," he added. "I think that's what parents really appreciate. It's a lot of fun but we learn [about values and good sportsmanship from the athletes] too."

The Final Stretch

As the only Brantford athlete representing Special Olympics Canada in track and field in Shanghai, Reisha is "thankful" for the opportunity presented to her by the organization. "[I'm going to] try my best and have fun. I'm really excited!" she exclaimed.

In addition to her parents and brother who will be accompanying Reisha to Shanghai, she will have the support of friends, family and community members back home, all of whom have faith in her ability to excel. As Reisha gears up for this momentous challenge, Brown speaks on behalf of everyone in extending her best wishes and confidence around Reisha's participation in the Special Olympics: "I think Reisha fits the motto of Special Olympics very well: 'Let me win, but if I cannot win, let me be brave in the attempt.' I'm 100 percent sure she will give her personal best." ■

Destined for great things in China, EF looks forward to featuring exclusive updates from Special Olympics Canada and from Reisha herself in our next issue.

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Sure I can

A column dedicated to
living & succeeding with a disability



Assistance comes at a price

by MICHAEL LIFSHITZ, CA, MBA

Avid *EF* readers may recall a column I wrote last year entitled “Accepting Help is a Sign of Strength, Not Weakness” (Winter 2006, Vol. 2 No. 3) in which I underscored the benefits of employing aids and adaptations as a means of circumventing particular challenges posed by one’s disability. I would be remiss, however, were I to ignore the fact that these aids and adaptations come at a significant cost. In my own case for example, I require an adapted van complete with a ramp, six position rotating seat (so that I can transfer from my wheelchair to the driver’s seat) and a left foot accelerator (due to the fact that I have an artificial right leg). In 2004, the van’s adaptation came at a price in excess of \$30,000.

Whether for adaptive equipment, therapy, care-giving, respite services, or special education, exceptional parents are constantly shelling out money in extreme quantities. The following tips which I’ve assembled based on my experience as a person with a disability may help to defray some of your expenses.

Look for Provincial Government Assistance

Since healthcare is under provincial jurisdiction, government assistance generally begins at the provincial level. As programs vary from province to province, a first step



Whether for adaptive equipment, therapy, care-giving, respite services, or special education, exceptional parents are constantly shelling out money in extreme quantities.

might be to consult government publications to see what programs are available in your particular province, as well as the amount that your province agrees to subsidize. Quebec, for example, offers a vehicle adaptation subsidy program.

There are several challenges in obtaining government assistance that ought to be considered:

- *Long waiting periods* – Often, there are delays in getting files processed by the government. My advice is to

start the application process earlier than you require the adaptive equipment or program, so that by the time you do need it, your file will have worked through the system. For example, if your child needs an electric wheelchair or special computer equipment in order to attend school, I suggest applying for assistance six months to a year before the school year begins in order to ensure that you will receive the equipment on time.

- *Subsidies are inadequately publicized* – The best way to learn about existing subsidies is to consult professionals in the special needs field and other exceptional parents. Occupational therapists, doctors and fellow support group members are all excellent resources for they are often apprised of the latest government funding programs. You may also wish to expand your search via the internet.
- *Arbitrary rules* – As with many bureaucratic structures, the rules

Sure I can

put in place by government bodies may seem arbitrary and illogical to the average person. In Quebec, for example, the Société de l'assurance automobile du Québec (SAAQ) will cover the cost of a vehicle's adaptation. However, the commission will only cover the cost of adaptation once every five years and it regulates which vehicles can be adapted. As such, I was forced to choose a vehicle that conforms to the SAAQ's list, which unfortunately does not have the best track record. I am now stuck with it until my "five-year term" is up, unless I wish to pay for the adaptation of a new vehicle myself.

Charitable Organizations

Various charitable organizations offer funding to assist people with disabilities. For example, the War

Whatever the source of funding, all possible avenues should be explored.

A disability can be challenging enough; financial limitations should not pose a further obstacle.

Amputations of Canada offers financial assistance to members of their Child Amputee Program to cover costs not covered by the government for artificial and recreational limbs.¹ Similar to Quebec's SAAQ van-adaptation subsidy, Ontario's March of Dimes will defray up to \$15,000 of the cost of a vehicle's adaptation, depending on family income.

Private Medical Insurance Programs

For parents who have private medical insurance programs through their employers, having your child included under the plan as a dependent is a very good idea. Call your insurance company to determine if you are entitled to any benefits that you may have overlooked when reading your plan.

Whatever the source of funding, all possible avenues should be explored. A disability can be challenging enough; financial limitations should not pose a further obstacle. ■

For more information about Michael Lifshitz's activities, visit www.myspace.com/mikelifshitz. Contact Michael at sureican@exceptionalfamily.ca

¹ Recreational limbs are prosthetics which are adapted for various sports such as waterproof prosthetics for swimming, arm prosthetics with special hands to hold golf clubs or tennis rackets, or special equipment to help an amputee ski.



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DENTISTRY FOR EXCEPTIONAL FAMILIES

Children with Cleft Lip and Palate

EF presents the second article in a unique three-part series on Special Needs Dentistry

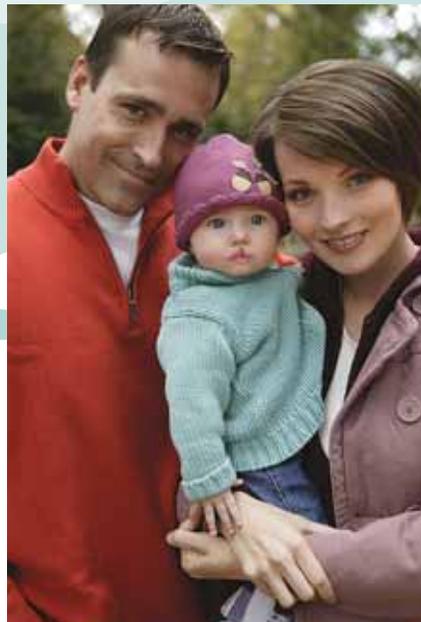
by DR. MICHAEL J. CASAS

While a wide variety of conditions are associated with facial differences in newborns, this article provides an overview of the dental experiences of children with cleft lip and palate as they and their parents navigate the long road from birth to final treatment of their condition.

Cleft lip and palate is a condition that may occur if facial development is disrupted during the first trimester of pregnancy, resulting in an incomplete fusion of the roof of the mouth. It occurs in approximately two out of every 1000 births. The causes of cleft lip and palate involve multiple genetic and environmental factors; no single factor has been demonstrated to produce cleft lip and palate. Clefting can affect the right or left upper lip or both sides simultaneously.



Unilateral cleft lip and palate in a baby girl



Immediately obvious at birth, the condition arouses significant anxiety in most families and unique hurdles need to be surmounted instantly.

Immediately obvious at birth, the condition arouses significant anxiety in most families and unique hurdles need to be surmounted instantly. Parents, for example, are confronted with the emotional impact of the

arrival of a child with a facial difference. For infants, clefting of the lip and/or palate produces feeding difficulties that can complicate breast-feeding or the use of regular baby bottles. With expert



Same child after surgery

feeding support and specially-designed baby bottles, the initial difficulties with feeding can be overcome.

Despite this difficult start, the prognosis for children with cleft lip and palate is excellent. Specialized surgeries, orthodontics and dental care that cover the period from birth to early adulthood can produce excellent functional and esthetic outcomes for affected children.

The benefits of a multi-disciplinary team

Since cleft lip and palate directly affects development of the mouth and adjacent structures, it is no surprise that children with cleft lip and palate and their parents will spend many hours with the dentist. When possible, it is best to seek care from dental specialists who are members of a hospital-based team with expertise in the care of children with facial differences. A multi-disciplinary team of health-care professionals best manages the complex needs of children with cleft lip and palate, as both the functional and esthetic hurdles that comprise cleft lip and palate are beyond the scope of treatment for

Sample Chronology of Interventions for Children with Cleft Lip and Palate

First year of life

- Infant feeding support
- Assessment by orthodontist/craniofacial team at multi-disciplinary treatment center
- Infant pre-surgical orthopedics
- Surgical lip repair
- First visit with pediatric dentist
- Surgical palate repair
- Placement of ventilating tubes for children with persistent middle ear infections

Age 1-7

- Assessments to document growth & development, hearing, speech, dental status
- Replacement of middle ear ventilating tubes (as required)

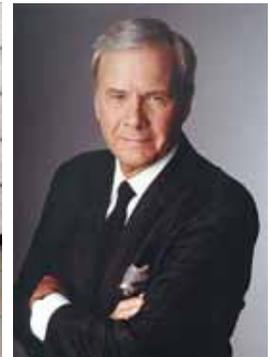
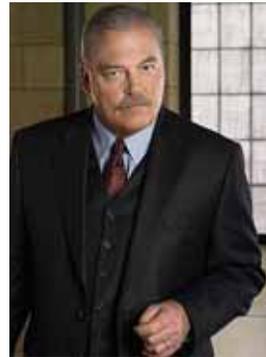
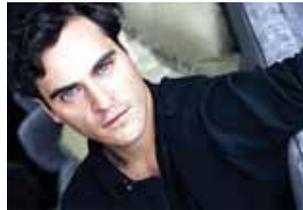
Age 8-22

- Orthodontic & surgical interventions to correct dental relationships
- Definitive prosthetic & cosmetic dentistry

any one healthcare specialty. The multi-disciplinary hospital-based teams who treat children with cleft lip and palate commonly consist of plastic surgeons, pediatric dentists, orthodontists and speech & language pathologists as core team members. Additional team members include oral and maxillofacial surgeons, prosthodontists (dental specialists in prosthetic replacement of oral structures), otolaryngologists, audiologists, pediatricians, psychiatrists, psychologists and social workers who all make significant consultative and therapeutic contributions to the child's care. Among the benefits of care provided by hospital-based teams is simplification

of information-sharing and coordination of treatments among the professionals involved in the child's care, convenient referrals to other relevant health care providers and sufficient patient volumes to allow development of clinical expertise within the team.

surgery. A visit to the pediatric dentist is commonly planned for approximately 3 months of age after lip closure surgery is completed. This visit allows the dentist to examine the child and initiate decay preventive measures and forecast future care for the parents. These early assess-



A cleft did not stop these famous people from succeeding. (L-to-R): actors Joaquin Phoenix and Stacy Keach, former news anchor Tom Brokaw

Early in infancy, a series of appointments with plastic surgeons, orthodontists and pediatric dentists begins. Very early intervention with pre-surgical orthopedics under the care of an orthodontist is often undertaken to prepare the lip for surgical closure of the cleft by a plastic surgeon or in some regions, an oral and maxillofacial surgeon. This orthodontic appliance treatment helps mold the lip into position to optimize the lip closure

and interventions are crucial for long-term management of the child's condition as dental decay and trauma may have a more significant effect for a child with cleft lip and palate than for an unaffected child.

Additional considerations

Children with clefts may be more susceptible to dental caries due to altered development of the enamel



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Financial assistance for parents of children with cleft lip and palate and other facial differences

Pediatric dentists in community practice or in hospital departments will assist parents to find out how their provincial program works. While assistance varies by province, it is essentially the same. Most plans cover some or all of the costs of orthodontics, prosthodontics (implants and individual tooth replacement) and oral and maxillofacial surgery. Two typical programs are Ontario and British Columbia.

Ontario: Children are covered from birth to age 22 for 75% of the cost of orthodontics, prosthodontics, oral and maxillofacial surgery and some other services. Depending on the treatment, there are maximums for some facial differences. Children must be eligible and registered at a children's hospital program by age 18.

British Columbia: All eligible and registered children are covered for 100% of the cost of orthodontics. There are maximums for some treatments. Treatment must begin by age 18.

on teeth adjacent to the cleft. Children with clefts may have hypoplastic teeth (poorly formed or misshapen with soft and discolored enamel), extra teeth or missing teeth around the cleft. Additional preventive measures and home care may prevent decay and early loss of teeth that may be strategic to the long-term dental and surgical treatment plan for the child. After repair of the lip, the palate is usually repaired by 12 months of age. Avoiding oral infection from decayed teeth in the period around the time that the palate is repaired is crucial to optimize the results of palate surgery. Similarly, regular examinations and preventive procedures can optimize oral health for future orthodontic, surgical and prosthetic care.

Throughout the toddler years, the child with cleft lip and palate may be affected by a higher than normal rate of ear infections that may produce impaired hearing. Oral antibiotics taken for these infections can increase the risk of tooth decay

Final treatment results are usually not realized until the early adult years when facial growth is complete.

as they are often sugar-based. Hearing tests and speech and language therapy are often required to help children overcome speech disorders that result from speaking with altered oral structures and hearing impairment from recurrent ear infections.

When the child enters the pre- and early adolescent period, long-term plans for orthodontic, jaw surgery and prosthetic dentistry are formulated. Families are commonly offered a number of treatment options and make decisions for the

future care of their child. These decisions surround the type of jaw surgery, if any, their child will have, which cosmetic or prosthetic procedures may be helpful and the most appropriate timing for these interventions. Final treatment results are usually not realized until the early adult years when facial growth is complete and orthodontics, jaw and cosmetic surgery and final esthetic dental procedures can be finalized.

Many resources are available to parents of children with facial differences. Children's hospitals across Canada provide services (consultative and therapeutic) for children with special needs.¹ Umbrella advocacy organizations such as About Face (www.aboutfaceinternational.org) provide information, peer support and even summer camp experiences for children with facial differences as well as links to other advocacy organizations that have a focus on specific facial conditions or syndromes. Provincial governments provide special funding to assist with the significant dental costs that parents will incur in the course of treatment of their child's facial differences (see sidebar on this page). While the birth of a child with cleft lip and palate starts families on a long road through the healthcare system, the coordinated efforts of specialized team members can help families and children make this journey a successful one. ■

Dr. Michael Casas is a Staff Pediatric Dentist, Division of Pediatric Dentistry and Project Director, Research Institute, The Hospital for Sick Children, Toronto. He is Associate Professor of Dentistry, University of Toronto and the Principal of Specialty Practice of Pediatric Dentistry in Etobicoke.

¹ For a complete listing of Canadian Children's Hospitals with Departments of Dentistry who service exceptional children, please refer to the previous article in this series, Kenny, Dr. David J, "Dentistry for Exceptional Families: Maintaining Oral Health is a Lifelong Relationship", *Exceptional Family* Vol. 2 No. 4 (Summer 2007), 28-31.

VISITING THE DENTIST WITH YOUR EXCEPTIONAL CHILD

*How to make the experience
something to smile about*

An EF bonus as part of our three-part series on Special Needs Dentistry



by AVIVA ENGEL
with contributions from
DR. DAVID J. KENNY

Maybe it's the sound of drills, the site of needles or the helpless feeling of having someone stand over your mouth with a pair of forceps that causes many adults to equate visits to the dentist with stressful feelings. Whatever the reason, many of us can certainly appreciate a child's apprehension around the same experience. In the case of exceptional children who may not understand what a "check-up" is all about, dental visits can pose an overwhelming and sometimes frightening experience. Knowing what to expect beforehand often helps to demystify the experience and assuage many fears that might otherwise make the event traumatic. The following dentist-approved tips may help ease your children's encounter with the "tooth doctor":

A waiting room full of happy, noisy children serves to buffer the sound of crying patients who may inadvertently influence your son or daughter.

Finding the Right Dentist

- Before choosing a dentist for your exceptional child, ask around and seek the advice of other experienced parents. Get referrals from friends or your pediatrician for a qualified professional who is both patient and compassionate. Depending upon your child's

disability, he or she may

benefit from a dentist who specializes in special needs dentistry (see article by Dr. David J. Kenny in Vol. 2 No. 4 "Dentistry for Exceptional Families: Maintaining Oral Health is a Lifelong Relationship.")

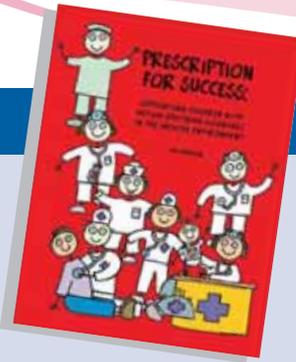
- Don't assume that a *pediatric* dentist is naturally good with children. If possible, arrange to meet with a new dentist alone prior to your child's visit in order to assess his or her personality and determine if he or she is likely to have a good rapport with your child.
- Some dentists' offices are kid-friendly, replete with books and toys. While waiting-room activities should not be the determining factor when choosing a dentist, they certainly help to make the overall experience all the more enjoyable for you and your child. A waiting room full of happy, noisy children also serves to buffer the

EF Extra! EF Extra!

While medical visits can be anxiety-provoking for any child, the often confusing and overstimulating environment of a hospital, dental office or doctor's clinic can totally overwhelm children with autism spectrum disorders and other developmental disabilities. Because of the unique needs of children with cognitive challenges, it is extremely important to pay special attention to the details of their experience in the medical environment. Unfortunately, medical staff are often not specifically trained to deal with such circumstances, whether during routine checkups, dental cleanings or even more potentially traumatic experiences, like surgery.

Designed to ease the medical experience for everyone involved, Jill Hudson's, **Prescription for Success: Supporting Children with Autism Spectrum Disorders in the Medical Environment** (Autism Asperger Publishing Company, August 2006) presents key interventions and assessments that medical staff, parents, educators and other service providers can use to more effectively interact with and support exceptional children in the medical setting.

An accompanying CD offers forms, activities and games that incorporate pictures of objects that children may encounter in various medical environments.



sound of crying patients who may inadvertently influence your son or daughter.

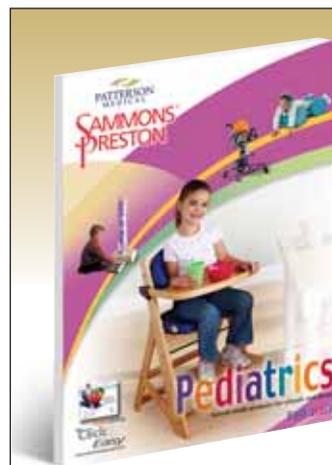
Make the Visit a Positive Experience

- Don't wait until an emergency comes up or you suspect that your child might have cavities in order to introduce him or her to the dentist for the first time. This may force the dentist to undertake treatment on the first visit that will be stressful for the child, the parent and the dentist. Instead, book a preparatory appointment so that your child can visit the office, meet the dentist, see the equipment, sit on an examination chair, smile, and see other happy children in the waiting room.
- Before the actual visit, read your child books about teeth, oral

hygiene and the experience of going to the dentist. Explain the importance of regular dental visits and stress the dentist's vital role in maintaining the health

of your child's teeth. Frame the experience positively.

- If the dentist permits, take your child along to a sibling's appointment (or your own) if possible, so that he or she can sit in the examination chair and observe that the experience is generally a pleasant one (providing you're not there to have a root canal!). Ask the hygienist to explain what he or she is doing on the patient to the child who is observing, or provide your own running commentary.
- Some dentists reward patients with small tokens that serve as incentives for them to cooperate. If your dentist does not offer prizes, consider bringing your own along, should the appointment prove stressful.
- Above all, model and practice good dental hygiene on a regular basis to ensure that your child's trip to the dentist will perpetually be cavity-free. Remember the motto "cavity-free means carefree"! ■



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Woman gives unprecedented donation to daughter

A 35-year-old Montreal woman has frozen some of her eggs for her 7-year-old daughter so that the girl can give birth in the event that she becomes infertile as an adult. The girl has Turner syndrome, a genetic condition that affects about one in 2500 girls that can lead to premature menopause and infertility, kidney and heart problems, growth, hearing and visual challenges and learning difficulties. The mother-daughter donation marks the first of its kind in the world. McGill University Health Center's ethics committee approved the procedure, which was conducted under the direction of doctors from McGill's reproductive center. According to Dr. Seang Lin Tan, professor and chairman of obstetrics and gynecology at McGill, "85 percent of the eggs survive freezing and then there is 40 percent chance of a live birth." If the girl chooses to use her mother's eggs in the future, the girl's offspring would also be her half-sibling.



Kids widely prescribed antipsychotics to treat non-psychotic disorders

Canadian children are increasingly being prescribed atypical antipsychotic medication (ATAs) for their non-psychotic symptoms such as impulsivity, depression, anxiety and frustration, according to a nationwide survey conducted on child psychiatrists. Out of 176 doctors surveyed, 51.2 percent prescribed ATAs to kids with ADD, 89.4 percent used ATAs to treat PDD, 73.5 percent used them to treat Tourette syndrome and 48.2 percent prescribed ATAs to kids with mental retardation.



ATAs block dopamine in the brain, a chemical associated with aggression and impulsivity. Originally developed to treat schizophrenia, the drugs include risperidone (Respirdal), olanzapine (Zyprexa) and quetiapine (Seroquel). None has been officially approved for children. While most were prescribed to

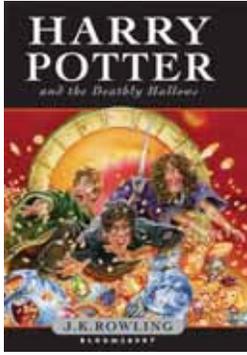
kids over 13, 12 percent of ATAs were given to children under 8 and as young as 3. According to the survey's lead author Dr. Tamison Doey of University of Western Ontario, although the drugs are helpful, symptoms recur once the medication stops, suggesting there may be a need to take them long-term – the implications of which are unknown.

ATAs cause significant weight gain. Researchers at Johns Hopkins University fear the drugs might cause insulin resistance in children, which could put them at increased risk of Type 2 diabetes and heart disease in adulthood.

Man in Motion moves Alberta government



The Alberta government recently pledged \$12 million over the course of three years to Rick Hansen's foundation. The funds will be applied to spinal cord research, treatment and services. Rick Hansen became paralyzed at the age of 15 as a result of a car accident. In 1985, he launched his Man in Motion Tour and travelled over 40,000 km in his wheelchair to raise awareness and support for his cause. In the course of two years, Hansen raised \$26 million for spinal cord research.



CNIB volunteer produces Harry Potter audio book in record time

Fans of J.K. Rowling’s Harry Potter series who have visual impairments will be able to access an audio version of the seventh and final installment as early as this month, thanks to a dedicated Toronto woman. When *Harry Potter and the Deathly Hallows* was released worldwide on July 21, Anne Saunders, a volunteer CNIB Library audio book narrator, purchased a copy and rushed to read the best-seller at the CNIB Library recording studio over a span of 10 days. The audio book was then produced in enhanced MP3 format and has been mailed on CD to CNIB clients across Canada. It is also available online. An average CNIB audio book can take anywhere from three months to a year to produce because the work is done entirely by volunteers. Given the series’ extreme popularity, Saunders’ goal along with the CNIB was to have *Harry Potter and the Deathly Hallows* available to people with vision loss as close as possible to the book’s release date.

Risk factors for autism may be predicted as early as 6 months old

Researchers at Hamilton’s McMaster University, The Hospital for Sick Kids in Toronto and the IWK Health Centre in Halifax have identified specific behaviors that can predict whether an infant will develop autism with remarkable accuracy. The findings are the result of an ongoing study of 200 Canadian infants between the ages of birth to 24 months who are siblings of children diagnosed with autism. In the absence of a standardized tool to measure autistic behaviors in infants under 18 months old, the researchers created the Autism Observation Scale for Infants (AOSI) which charts the development of babies as young as 6 months against 16 risk factors for autism. The markers include a passive temperament, not responding to one’s name, a tendency to fixate on objects and not smiling in response to others’ smiles. Led by Dr. Lonnie Zwaigenbaum of McMaster’s Children’s Hospital and Dr. Susan Bryson of IWK Health Centre, the study is the largest of its kind in the world and has gained international attention, now involving researchers in 14 cities across North America. According to Zwaigenbaum, almost all of the children diagnosed with autism by the age of two had seven or more of the high-risk markers at one year of age.



Gene linked to childhood blindness comes at an auspicious time



A McGill University researcher and his international team of scientists have pinpointed one of the genes responsible for Leber congenital amaurosis (LCA), the leading cause of blindness in babies and young children. The discovery of the gene, LCA5, coincides with the world’s first human gene-replacement therapy trial that began recently in London and Philadelphia. Doctors there are attempting to replace another defective gene linked to LCA – RPE65 – with a healthy gene.

While it took nine years from the time RPE65 was discovered until the human clinical trial could be attempted, leading researcher Dr. Robert Koenekoop is hoping to bring LCA5 to clinical trial in as early as two or three years. Approximately 200,000 people worldwide are born with LCA, half of whom are Canadian.



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PRESERVING YOUR EMOTIONAL, SOCIAL & INTELLECTUAL EQUILIBRIUM

*Boosting your energy reserves requires
more than merely addressing your physical health*

by HEATHER FAWCETT

In the last issue of *Exceptional Family* we explored ways in which you can boost your physical energy reserves amidst the daily responsibilities of exceptional parenting. While good eating habits, exercise and adequate rest launch you on the road to wellness, the journey mustn't stop there. Caring for yourself also means tending to your emotional, social and intellectual needs too.

As the parent of an exceptional child you may have little time to consider your own needs. Between the day-to-day care, specialist appointments, school meetings and other demands of exceptional parenting, you may feel lucky just to be able to grab a shower. But you don't have the luxury of waiting for less hectic times either. Since you will likely be "on call" around your child's needs for an indefinite period, the "right time" may never come. So, take the time now to make yourself a priority. Ask family, friends and neighbours to pitch in so you'll have more time to socialize, pursue interests,



*Since you will likely be
"on call" around your
child's needs for an
indefinite period, the
"right time" may never
come. So, take the time now
to make yourself a priority.*

and enjoy activities that give your life meaning.

Relationships Make Us Happiest

Although many people tend to equate happiness with wealth, luxuries or

view it as something unattainable altogether, research shows that it's close relationships with family and friends that make us happiest.¹ Yet, relationships take time and energy to nurture, a feat that may pose a challenge for many exceptional parents due to lack of energy, availability, money and child care options.

To develop meaningful relationships, try these strategies:

1. Seek support and friendship from like-minded parents through disability support groups and networks. Contact local disability agencies or community hospitals to find groups or conduct an internet search for online forums on disability association websites.

2. Cultivate friends outside the special needs world too! Friends who parent exceptional children offer understanding and support but they may not always share your interests. Join a club, pursue a hobby, or get out into your community to meet others

1 Ed Diener and Martin E. P. Seligman, "Very Happy People." *Psychological Science* 13, no. 1 (2002): 81-4.

with similar interests. Conversations with neighbours, co-workers and fellow worshipers, for example, offer welcome diversions from your daily challenges and a chance to talk about more than your special needs child.

3. If getting out with friends is difficult, invite them in. Don't wait until the house is pristine, since it may never be! Tidy up the foyer and sitting room, do a quick clean of the bathroom and close doors on the rest. Don't feel you have to go all out. Conversation shared between friends is most important, not the elaborate meal.

4. Be supportive of your friends by checking in regularly – pick up the phone or email. You may think their struggles are



not as intense as yours but all families have challenges. Support your friends during their tough times and they will be there for you too.

Nurture the Relationship with your Partner

A special needs child in the family can stress family relationships. When your child is diagnosed, for example, your partner may react differently than you and it may be hard to relate to each other's feelings. One partner may take action while the other retreats to the safety of hobbies or work. Parents may disagree on par-

enting strategies such as discipline or one parent may feel he or she is doing the lion's share of the work.

Here are ways to get your relationships back on track:

1. Recognize that each of you may grieve in different ways – often women are raised to talk openly about their feelings while men may believe they should keep their feelings to themselves. Seek emotional support elsewhere if your partner isn't able to provide it.

2. Make time to connect with your partner. Find a few minutes each day to talk to one another – not just about your children and their needs. When time allows, add some romance by lighting a candle and enjoying a glass of wine or chocolate.

3. Work as a team. Learn about your child's disability together. Attend conferences or read books together. Try to schedule appointments when you can both attend. Your parenting roles can be different, but you need to be together on the important issues.

4. Plan an overnight, weekend, or week-long getaway with your partner. If family or friends can't help with childcare, investigate respite funding or facilities in your community. Or modify your family getaway to get time



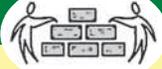
alone by bringing along a support worker. See if the motel/hotel offers specialized babysitting services.

5. If tension between you and your partner is damaging your family life, seek counselling as a couple or family. Ask your doctor to recommend a marriage or family counsellor.

Recognize the Meaningful Moments

Besides close relationships, your emotional and intellectual sides

TAC TICS RESOURCES SERVICES
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peer or parent
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need nurturing too. Happiness stems from fulfillment in many areas. According to psychologist Martin Seligman, author of *Authentic Happiness: Using the New Positive Psychology to Realize Your Potential for Lasting Fulfillment*, the happiest people are those who seek three types of experiences:

1. Pleasure (pure in-the-moment emotion): For instance, very little can match the intense joy you feel when your child accomplishes a skill which he or she has struggled hard to achieve – one that a typical family might take for granted.

2. Engagement (deep involvement with family, friends, work, hobbies, etc.): Not only does exceptional parenting demand the support of family and friends; it also requires the acquisition of knowledge and skills in nursing, research, advocacy and time-management.

3. Meaning² (using personal strengths to serve the greater good): Parents often speak of the gratification and renewed positive perspectives they derive from applying these skills in caring for their child and others.

By this definition, parents of exceptional children have rich opportunities for life satisfaction.

When your child has medical setbacks, exhibits challenging behaviours, or you're struggling to obtain



services, it can be hard to stay positive. Try these strategies to add enjoyment and purpose to your life:

1. Take the time to appreciate the beauty around you – a beautiful sunset, your child's smile, a bird's song.

2. Count your blessings. Take time each day to write down three things that went well

as a tangible reminder of all the positives in your life.

3. Pursue an activity solely for your own enjoyment or intellectual growth. Reclaim a hobby or find a new one, take a course, or join a club or sports team. List any barriers such as lack of energy, time, childcare or equipment and brainstorm solutions.

4. Increase activities that use your strengths to help others. Doing so is both rewarding and adds to your sense of competency and self-worth. Offer your good listening skills to a friend. Share your craft talents at a local school or childcare centre. Or, put your organizational and communication skills to use at a local non-profit organization.

5. Nurture your inner peace. Slow things down by cutting back on commitments, spending more time outside or enjoying the simple things in life that make YOU happy (reading a book, gardening, meditation, nature, dancing, art, or whatever holds meaning for you).

Take the time to keep yourself strong – physically, emotionally and socially. The better you feel, the better you can take care of your family for the long haul. ■

2 Martin E. P. Seligman, *Authentic Happiness: Using the New Positive Psychology to Realize Your Potential for Lasting Fulfillment*. New York: Free Press, 2002.

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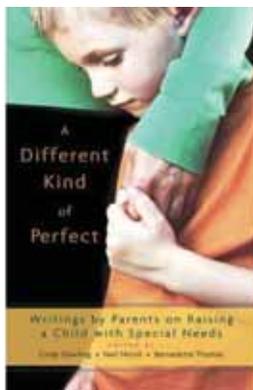
Heather Fawcett is the mother of a teen with Asperger Syndrome. She gives workshops on life balance based on the book (co-authored with Amy Baskin) *More Than a Mom: Living a Full and Balanced Life When Your Child Has Special Needs*, Woodbine House, 2006.

& Classics

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

A Different Kind of Perfect

Writings by Parents on Raising a Child with Special Needs
 Edited by Cindy Dowling,
 Neil Nicoll, Bernadette Thomas
 Trumpeter Books, 2004
 262 pages, \$22.95



Inspired by their own experiences and unique emotions as exceptional parents, Cindy Dowling, whose son has autism, and Bernadette Thomas, whose son has Down syndrome, set out to collect writings from fellow parents of children with physical and cognitive disabilities from around the world. Their search yielded enough material to compile a heartwarming anthology of reflections from Canadian, American, European, Australian and Asian mothers and fathers entitled *A Different Kind of Perfect: Writings by Parents on Raising a Child with Special Needs*.

Divided into theme-based segments that include the multiple stages from denial to acceptance that parents encounter upon learning their child's diagnosis, the book also touches upon the topics of Empowerment, Marriage, Family and Friends, Love

*Writing about your child's disability is damned hard.
 It takes you to places you don't necessarily want to go.
 It opens old wounds and summons new fears.
 It forces you to confront yourself, to gaze into the mirror
 and write down what you see. For most of us, the face that
 stares back is not always the one we show to the world.*

- *A Different Kind of Perfect*

and Joy, Spirituality and Laughter. Each chapter begins with a thought-provoking quote and an introduction by Neil Nicoll, a psychologist at Vern Barnett School for Children with Autism in Australia.

Much like the Chicken Soup for the Soul® series, *A Different Kind of Perfect* offers something for everyone and features bite-size readings that can be

enjoyed piecemeal. Resources, recommended readings and an appendix featuring suggestions on how to unwind are an added bonus to this wonderful book, which is an invaluable tool for both parents of newly-diagnosed children and those who wish to begin the long healing process of coming to terms with the daily challenges of raising an exceptional child. ■

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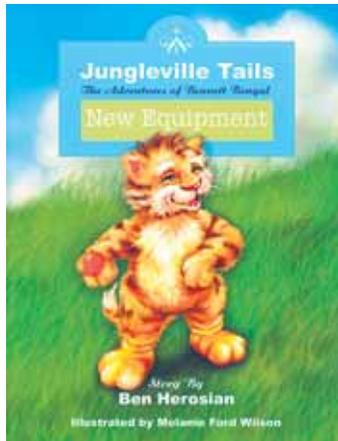
Jungleville Tails, The Adventures of Bennett Bengal: New Equipment

By Ben Herosian

Illustrated by Melanie Ford Wilson

Lilyfield and Company, 2005

16 pages, \$14.00



Geared for children ages 4 to 8, *Jungleville Tails, The Adventures of Bennett Bengal: New Equipment* recounts the delightful story of Bennett Bengal, a lovable tiger cub born without feet. An alter ego to author Ben Herosian, who was born with a rare genetic condition called Moebius Syndrome that left him without feet, a missing left hand and other significant anomalies, Bennett lives in the utopian “far away land” of Jungleville which is inhabited by animals “of all shapes and sizes” who work and play “together, side by side.”

When Bennett’s peers leave the popular grassy field for the more mature hangout of an adjacent concrete courtyard, Bennett is excluded due to the courtyard’s hard, hot surface which his parents caution would be potentially hazardous to a tiger without paws. Determined to test their advisory, Bennett scrambles to the courtyard

where he inevitably suffers a minor injury, inspiring his parents to have Bennett fitted for prostheses. The following day, Bennett and his parents visit the local Rehab Center for Young Animals, where he gets

fact that the entire process from start to finish takes significantly longer than a single day.

The book’s only significant shortfall is the quality of its saddle-stitched

The Jungleville Rehabilitation Center for Young Animals was an amazing place. Animals of all shapes and sizes who needed special equipment were frolicking outside the building...

There was a giraffe with a prosthetic leg playing tag with a gorilla with a prosthetic arm and a wolf zooming around in a shiny electric wheelchair.

- The Adventures of Bennett Bengal: New Equipment

prosthetic paws. Following a celebratory stop at the local Burger Lion restaurant (which he walks to independently) Bennett joins his friends in a game of basketball on the concrete courtyard.

Recognizing the story’s fairytale quality and the haste with which Bennett is fitted and becomes comfortable with his new prostheses, parents may wish to highlight the

binding and flimsy cover which make it more susceptible to wear and tear than typical hard cover books.

Nevertheless, vivid illustrations coupled with a feel-good message and a validation of children’s apprehension around the experience of being fitted for prostheses make this “Once upon a time” tale an instant classic. ■

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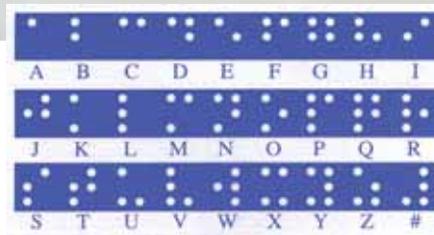
Braille is a language all its own

by KIM MANNIX VERMETTE

Many readers embrace the special joy that comes from opening a favorite book, taking in the words on a page and letting their imagination paint vivid pictures in the absence of visual images. Sometimes we're so inspired by the power of words that we dream of penning our own stories or poems and sharing our creations with others.

Seventeen-year-old Carolyn Naylor, a Nova Scotia native with low-vision, started putting her ideas to the page at age 11 and hasn't stopped since. When she began learning Braille in Grade 6, she discovered a whole new way to record her stories. "I love writing stories," says Carolyn. "It's fun, it makes me happy and it's probably my most favorite thing to do."

Carolyn has optic nerve atrophy, and though there has been little change in her vision since the



The alphabet, numbers, musical notations and other symbols for math and science that most of us see in print can be replicated in Braille.

condition was first discovered when she was two years old, she and her parents realized that learning Braille was important – both as a means of preparing her for the possibility of her vision deteriorating further, and also as a way of increasing her literacy skills.

Braille is a code made up of six dots arranged in different combinations to convey information. It is usually written with abbreviations and contractions, of which there are many. The alphabet, numbers, musical notations and other symbols for math and science that most of us see in print can be replicated in Braille. As with any new language, becoming fluent in Braille requires one to learn proper spelling, punctuation and grammar. Carolyn's efforts to become fluent in Braille are ongoing, and she often needs to devote time to studying it over and above her regular school course load. She hopes to complete her studies in Braille by the time she's ready to graduate from Grade 12.

"I'm finding that the more she learns Braille, the more she looks for it in her environment," says her mother, Nancy. "For example, she'll look for the buttons in elevators that are marked in Braille. So I know

it's becoming more and more important to her," she says.

Carolyn's devotion to Braille as well as her love of writing, is paying off. Last year Carolyn entered the Creative Writing and Braille Accuracy Competition, hosted annually by the Canadian National Institute for the Blind (CNIB), as part of its Braille Conference held in Toronto each October. She won first prize in her age category for her short story about two people surviving an adventure on a raft and overcoming danger by relying on their friendship. "I was so excited when they told me I had won. I think I screamed," says Carolyn, laughing.



Lisa Kovac, (left) winner of the Creative Writing and Braille Accuracy Competition, in the grade 10-12 category poses with author and competition judge Marnelle Tokio and Carolyn Naylor, who also won first place in the competition's Grade 7-9 category.

heavy metal typewriter. The Braille stylus or the machine is used to create raised dots on Braille paper.

"In preparing her story for the competition, Carolyn often complained about sore fingers, but in the next breath was happy with how much she had accomplished that day," explains Nancy.

While the competition is a great way for participants to show off their creativity, there's a bigger purpose: to showcase the CNIB's belief in the importance of Braille literacy. Shelagh Paterson, director of advocacy, sales and marketing with the CNIB library in Toronto, explains that learning to read and write Braille is as important for persons who are blind or have visual impairments as learning to read and write print is for people with sight. "Reading Braille is equivalent to reading print. Both ensure literacy, which we all need to have to function in society," she says.

Learning to read and write Braille is as important for persons who are blind or have visual impairments as learning to read and write print is for people with sight.

Braille as a complement to technology

Though she does have some vision, Carolyn was encouraged to learn Braille by her parents and teachers, who all saw it as a means for her to have more independence. Nancy says that even though her daughter was already very self-sufficient, learning Braille has helped her succeed in school and will aid in future employment. But initially she wasn't sure it was necessary. "Carolyn's not blind and my husband and I often struggled with, 'Why does she need to learn Braille?' – especially in this day and age with so much technology out there. But we have come to see how it can help so much with reading comprehension, and how much Braille literacy can enrich her life."



A Perkins Braille

The competition provides an opportunity for students in Grades 1 through 12 of varying Braille competency levels to practice their skills while having fun. Young adults who are eligible for CNIB's services can participate by entering original

poems or short stories that have been manually created through the use of a slate and stylus, or through a Perkins Braille which is a kind of

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Nancy adds that as much as technology has advanced to help those with vision impairments, it cannot entirely replace the need for Braille. In school and in the workplace, knowing Braille makes it possible for blind people and vision-restricted persons to read and take notes independently, and increases the amount of written material that is accessible to them.

According to CNIB research, there are many ways in which understanding Braille can have a positive impact on the lives of those who learn it. As the Canadian National Institute of the Blind succinctly states on its website, "Braille is a building block of literacy. Literacy is

"I cannot imagine life without Braille.

Scanners and technology are great, and wonderful for proofreading, but you still need that physical ability to know what words are."

a building block of independence." Without Braille, people who are blind or have low-vision are largely dependent on computers with voice synthesizers. While such technology offers several benefits, it cannot replace the usefulness of Braille for things such as labelling CDs, shampoo bottles and cans of food at home, for taking notes for presentations or writing personal messages to parents and caregivers.

Kim Kilpatrick, who works with Volunteer Ottawa in the nation's

capital, has been blind since birth. Like Carolyn, she also has a passion for words. "I have been writing stories, thank-you letters, doing my assignments and taking class notes in Braille ever since I was young," she says. "I cannot imagine life without Braille. Scanners and technology are great, and wonderful for proofreading, but you still need that physical ability to know what words are." Her passion for words has ultimately led

Kilpatrick to become a professional story-teller in her spare time.

Paterson, of the CNIB library, emphasizes that while listening to an audio book is one way of getting information, it's important for children to discover the written word for themselves. "They need to participate with their sighted peers. This includes reading the same books and working on the same



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assignments. Braille gives them the freedom to do this,” adds Paterson.

Nancy says she was thrilled to see Carolyn put her writing skills to use for the Creative Writing and Braille Accuracy Competition. “Her teacher saw it as a way for Carolyn to work on her Braille more thoroughly, so learning was really the goal and winning the competition was just a wonderful bonus. Carolyn worked so hard at it, too. If she made a mistake she was the first to notice and start over again. She was driven to complete it and be accurate as well.” The CNIB will stage the competition again this year and Carolyn has already submitted an entry.

And while she would love to win again – and get another chance to make the trip from Nova Scotia to Toronto – she says she will always treasure the experience of attending the Braille Conference and meeting so many young Canadians who are blind or have visual impairments who share her passion for telling stories. “I liked it so much, so of course I wanted to be a part of it again,” says Carolyn. “The conference was unforgettable.”



Blind woman writing using braille slate and stylus.

“The life-long benefits Carolyn will have from this experience have been amazing and we are thrilled to see [the event] continue.”

An added bonus for winners

An exciting feature of the competition this year comes from an interesting partnership between VoicePrint and the CNIB. Voice-

Print, a division of The National Broadcast Reading Service, airs “spoken word” versions of current newspaper and magazine articles, most of which are not immediately available in Braille format. Round-the-clock broadcasts, available through cable TV, satellite and the Internet, provide necessary information to all Canadians, but particularly to the 4.5 million citizens who cannot independently access print due to blindness, physical impairment or low literacy skills, for example.

VoicePrint shares CNIB’s belief in the importance of literacy and access to the written word for all people. This year VoicePrint will be participating in the annual Braille Conference by serving as host of a workshop, as well as by broadcasting audio versions of winning entries in the Creative Writing and Braille Accuracy Competition.

The goal is to have winners, including Carolyn if she triumphs again, visit VoicePrint’s national studios in Toronto and get the chance to share their words with all of Canada through a special broadcast. Nancy Naylor says she thinks the broadcast will be a fabulous way to spread the word about the importance of the competition through a service that also provides essential information to Canadians. “It’s a great way for the children to share their stories,” she says. “The life-long benefits Carolyn will have from this experience have been amazing and we are thrilled to see [the event] continue.” ■

For more information about the CNIB Braille Conference and the Creative Writing and Braille Accuracy Competition, visit www.cnib.ca. For more information about VoicePrint and to access a broadcast schedule and details about its special Braille-related programming, visit www.voiceprintcanada.com

 <p>LOCATION: Le Chateau Royal 3500 boul. du Souvenir Laval, Quebec</p> <p>NOVEMBER 8 & 9, 2007 7:30 a.m. - 4:30 p.m.</p> <p>Register today by fax at 514-345-1619</p> <p>Special Hotel Rates Available at the Radisson Laval 1-800-333-3333 Please mention the Miriam Foundation when calling www.goldlearningcentre.com</p>	<p>The Abe Gold Learning and Research Centre's 1ST ANNUAL SYMPOSIUM ON</p> <p><i>Autism and Developmental Disabilities</i></p>	
	<p>November 8, 2007 Keynote speakers/orateurs principaux (avec la traduction simultanée)</p> <ul style="list-style-type: none"> • Dr Robert Schultz • Dr Jeanette McAfee <p>Breakout Sessions/Choix de séances de travail 1:30 p.m. / 13h30</p> <ul style="list-style-type: none"> – Dr. Jeanette McAfee (English Session) – Dr. Shari Joseph (English Session) – Dr. Marie-Hélène Prud'homme (Session française) – Dr. Roger Godbout (Session française) – Dr. Guy Sabourin (Session française) <p>3:15 p.m./15h15</p> <ul style="list-style-type: none"> – Dr. Peggy O'Byrne (English Session) – Prof. Tara Flanagan (English Session) – Dr. Roger Godbout (Session française) – Dr. Ridha Joobar (Session française) – Michelle Dawson (English Session) <p><small>Registration deadline and cancellation must be received in writing by October 20, 2007 / Date limite pour s'inscrire et pour annuler votre inscription doit être fait par écrit et reçue avant le 20 Octobre 2007. • There is a 20% administration charge should you cancel your registration / Il y a une charge d'administration de 20% si vous annulez votre enregistrement.</small></p>	<p>November 9, 2007 Keynote speakers/orateurs principaux (avec la traduction simultanée)</p> <ul style="list-style-type: none"> • Helen Tager-Flusberg, Ph.D • Kathleen Quill, D. Ed. <p>Breakout Sessions/Choix de séances de travail 1:30 p.m. / 13h30</p> <ul style="list-style-type: none"> – Dr. Kathleen Quill (English Session) – Alice Bender (English Session) – Drs. Nathalie Garcin et Jennifer Nachshen (Session française) – Hugo Lamoureux (Session française) – Susan Senator (English Session) <p>3:15 p.m./15h15</p> <ul style="list-style-type: none"> – Ginette Bernier (Session française) – Michelle Lyon M.A. (English Session) – Dr. Leslie Klein (English Session) – Alice Bender (Session française) – Dr. Maria Ramsay (English Session)



The wish to keep our children close-by



Q I am the mother of a six year-old non-verbal, very docile daughter with autism whose psychological report indicates that she functions at the level of an 18-24-month-old. I am in the process of getting a divorce and I am concerned because her father is seeking 50/50 custody and visiting rights despite the fact that he was almost never present. I myself spent 24 hours a day with my daughter until she was three-and-a-half at which time I began to work one day a week, building up to my current employment of three days a week. I am fighting to keep the house which we have been living in since my daughter was born and knowing that she cannot tell me when she is unhappy I wonder what the consequences would be of her residing in two homes. When at the cottage with which she is familiar, after two days or so she will take me by the hand and bring me to the car to leave. If I am not mistaken, EF magazine recently published an article stating that the special needs of the child would have to be taken into consideration in the event of separation. Is there any other information you can provide for court purposes and to assist my lawyer in preparing my case, about the effects of divorce on a child with autism?

Most typical children appear to struggle with the move between two homes where the rules, limits, routines and expectations established by the respective parents tend to differ.

A Your letter reflects the pain and tension which you are no doubt experiencing as your life has taken this turn. Your concerns for your daughter's best interests under these difficult conditions are most understandable. I hope that you feel that you can ultimately rely on your lawyer to guide you through the complex legal process. While I myself have no legal background and am not a Registered Custody Evaluator, what follows is offered from my perspective as a marital and

family therapist and is based solely on your personal description of the situation.

Firstly, you raise the issue of maintaining continuity for your daughter. You observe that she shows

difficulty transitioning even to the cottage with which she is familiar. I would say that in my professional experience, most typical children appear to struggle with the move between two homes where the rules, limits, routines and expectations established by the respective parents tend to differ.

I would think that given your daughter's special needs which already reflect sensitivity to a change in environment, maintaining a sense of continuity around these areas would be especially important in allowing her to function optimally. This, combined with the fact that you describe yourself as her primary caretaker would suggest that she would be likely to manage best if she remains in your care.

In the ideal, being able to keep your current home would be helpful, if for no other reason than the elimination of the stress of moving. Should you be obliged to relinquish it however,

I am sure that over time, through your presence and the structure you provide, your daughter will make the adjustment to the new setting.

This is not to suggest that she would not benefit from having a connection with her father. The key is to find the formula that works for the individual child. Dr. Abe Worenklein alludes to this in greater detail in the Fall 2006 edition of *Exceptional Family*.¹

I would recommend that you get in touch with the professionals who have been supporting you and working with your daughter over the years. Because they know you both well, they may be in a position to offer their opinions to the court about the best plan for her.

Another option albeit a rather costly one, is to engage the services of a Registered Custody Evaluator with specialized training in the needs of exceptional children, who will do an extensive examination and produce a report for the court substantiating your daughter's needs for consistent and available parenting along with recommendations about how these needs should be met.

¹ Abe Worenklein, "In the best interest of the exceptional child: Determining living arrangements following separation and divorce", *Exceptional Family*, Vol. 2 No. 1, (Fall 2006) 30-33.



Q My 18-year-old son Jeremy was born with developmental delays and functions at the level of a nine-year-old. He has been receiving "life-skills" and "travel/safety awareness" training for months and according to his educator is now ready to take the bus to and from his rehab center on his own. While Jeremy is physically mature and broadly-built at 6'1, he is extremely juvenile and often behaves inappropriately in public (for example, he doesn't use a filter of any kind when speaking and frequently giggles uncontrollably). Rationally, I understand that letting him take the bus alone is an important step toward helping Jeremy gain a sense of independence and self-confidence, however I fear that people may take advantage of Jeremy's vulnerability and ridicule

or bully him. Until now, I have been driving him to and from the center and would be happy (and relieved, frankly,) to continue doing so indefinitely. I wonder what your thoughts are on this issue.

A Your letter underscores your struggle to foster your son's growth while still wishing so much to protect him.

In the tug-of-war between your rational judgement and your emotions, I hope that I can be helpful in encouraging you to give the former the winning advantage. But first I want to acknowledge that your anxious feelings are not unfounded.

*You are likely confronting
for the first time
Jeremy's rite-of-passage
into a world in which
he is symbolically and
actually moving away
from your authority.*

You know that due to his special needs Jeremy functions at an impaired level of judgement and that if left to his own devices he could possibly provoke others into responding to his inappropriate behaviour.

In addition, because at 18 you are reminded of his adulthood in the chronological as well as in the physical sense which is coinciding with his taking the step of independent travel, you are likely confronting for the first time Jeremy's rite-of-passage into a world in which he is symbolically and actually moving away from your authority.

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Like all parents you are facing the point where you must accept the fact that you cannot protect your child forever and that even if this were possible, it would be to the detriment of his development.

While no doubt, like all parents of a child with special needs you are particularly attuned to your son's vulnerabilities, it is still necessary to give Jeremy the opportunity to meet his full developmental potential by allowing him to take some calculated risks. I am quite certain that if you think back over the past 18 years, you will recall situations in which you have already done this successfully, such as having him attend school or participate in sports activities.

Granted, letting Jeremy take the bus alone is an even greater challenge for him and for you, since he will not have the same type of close supervision in this situation.

While you cannot expect to fully overcome your worries – and what parent can? – as a means of alleviating some of your anxiety, you might consider arranging a meeting with

Jeremy's educator. Even if you have previously been informed about the process of training you could ask for a review of how it evolved in your son's case so that you will be able to picture the gradual steps which led up to the conclusion that he is

Like all parents you are facing the point where you must accept the fact that you cannot protect your child forever.

ready for independent travel. You should feel free to share your specific concerns about his behaviour and inquire how this was factored into his training program.

Feeding your rational side with more information will help provide you with the necessary perspective that "life skills" and "travel /safety awareness" programs are indeed thoughtfully and sensitively designed to meet

the unique needs of the participants, in most cases with excellent results. This, in turn, will enable you to feel less emotionally conflicted about the plan and more collaborative with it.

If you are able to reign in your concerns enough to allow this step as another along the path of calculated risks which you are taking to maximize your child's growth and to support it more wholeheartedly, you will be more successful at channelling your emotional energy into offering encouragement to Jeremy which is what he needs most from you at this time.

I invite you to contemplate the profound thoughts of Helen Keller in her poem entitled Let Us Have Faith:

*Security is mostly a superstition.
It does not exist in nature,
nor do the children
Of men as a whole experience it.
Avoiding danger is no safer
in the long run
Than outright exposure.
Life is either a daring adventure,
or nothing.
To keep our faces toward change
and behave
Like free spirits
In the presence of fate
is strength undefeatable (sic). ■*

Do you have a question to Ask the Expert? Please send all queries to Veeta Engel at asktheexpert@exceptionalfamily.ca Confidentiality will be respected.

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



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Post-secondary educational opportunities for youth with developmental disabilities

by KENNETH C. POPE, LLB

As parents, we do our best to help open doors that will provide our children with opportunities to continue learning. Children with developmental disabilities may not be interested in or able to attend university or college, however this does not preclude their ability to develop other interests and skills through post-secondary educational opportunities. Registered Education Savings Plans (RESPs) facilitate a method of saving for such opportunities by allowing you to earn investment income in a tax deferred environment.

Individual plans can be set up for the benefit of an individual beneficiary while family plans accept contributions for more than one beneficiary. While there is no longer a maximum *annual* contribution to an RESP, the maximum *lifetime* contribution per beneficiary cannot exceed \$50,000. These contributions are not tax deductible. The Federal government provides a grant of 20 cents for each dollar contributed, up to a maximum of \$500 each year and a lifetime limit of \$7,200. These Canada Education Savings Grants (CESG) are only paid on the first \$2,500 contributed each year and only if an annual



(RESPs) facilitate a method of saving for educational opportunities by allowing you to earn investment income in a tax deferred environment.

contribution is made. A large lump sum contribution might compromise these grants, but the interest accumulating tax free on a lump sum of \$50,000 (presuming for example that grandparents decided to endow this amount as an “early” inheritance) would generate much more tax-free growth than the grants provide. This option may be useful for some families.

Recently the Federal government announced that there will be an

additional grant for families with an income below \$74,000. The grant on the first \$500 contributed will be 40% for families with incomes below \$37,000 and 30% for families with incomes between \$37,000 and \$74,000. Contributions can be made for a period of 21 years.

An RESP must be terminated by the end of the year that includes the 25th anniversary of the plan.

Disbursing RESP funds: Which schools and programs apply?

In order to disburse the funds from an RESP, a facility must be deemed a “designated educational institution” with a “qualifying educational program” under the Canada Student Loans plan. Alternatively, it can be certified by the Minister of Human Resources as an educational institution that provides courses related to the development or improvement of skills in a given occupation or vocation.

A “qualifying educational program” cannot span less than three consecutive weeks. Full-time students must spend at least 10 hours weekly on program-related courses or work, while part-time students must devote

at least 12 hours monthly of their time. The in-class portion of a recognized apprenticeship can also count as time spent. Part-time students can access up to \$2,500 of RESP funds per 13-week semester, or greater amounts if approved by plan administrators.

While a variety of courses offered at post-secondary schools currently meet these criteria, curricula can be created specifically to meet the special needs of adult children. For example, a group of exceptional families in Ottawa recently arranged a series of approved continuing education classes designed for their 25 children at Algonquin College in Ontario, all of whom had graduated high school at age 21.

In order to make post-secondary studies more attainable to exceptional people, students with disabilities now have the options of attending school on a part-time basis, accessing distance education courses through correspondence, participating in on-line learning opportunities, or studying via a variety of apprenticeship programs.

Once the money from the RESP has been distributed to the beneficiary, the income earned in the plan plus the amount of federal contributions are taxed as income of the beneficiary. As a student, your child likely

will not have much other taxable income and will be eligible for tuition and education tax credits, therefore he or she will have little to pay in taxes.

RESP funds should only be used to pay for education-related expenses such as tuition, books and



tutors. If a residential or meal plan comprises a component of your child's program, it is very important that the plan not be paid with RESP funds. Similarly, RESP money should not be used to pay for things that are covered by provincial disability benefits, such as shelter, clothes or food. Separate paperwork should be kept in order, otherwise there may be a deemed overpayment of provincial disability benefits and a surprise claw back of "overpayments" due to

simple misapplication of funds for the wrong use.

If your child chooses not to pursue post-secondary education

Parents have always had the assurance that if their child decides not to pursue post-secondary education, their capital contributions to the savings plan would be returned to them tax-free. They now have the additional assurance that up to \$50,000 of the income that accumulates in the RESP can be transferred into their RRSPs, to the extent that they have unused contribution room available.

Alternatively, parents can withdraw the RESP income and pay tax at their marginal rate plus an additional 20%, to offset the interest earned on the grant. The grant portion is returned to the federal government.

It is now also possible to roll over or transfer the educational assistance payments, without tax implications, to another family member, so long as the beneficiary is under 21 years of age and is related by blood or adoption. In the case of an RESP in the family plan format, educational assistance payments can be paid out to another family member as long as the same qualifying criteria are followed. ■

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Kenneth C. Pope, Lib. TEP is an estates and trusts practitioner specializing in assisting families with children with special needs. His practice is provincial and inter-provincial, dealing with Wills with Henson trusts, disability related tax issues and back filings, and with Ontario Disability Support Programme benefits and problems.



Reviewing the Travel Mailbag

by MIKE COHEN



Since I began writing this column two years ago I have received a lot of feedback from readers. In this edition I have decided to answer a few of the questions which have been sent my way.

1. My child is on the high-functioning end of the autism spectrum and thrives on consistency and a predictable schedule. Do you have any suggestions in terms of how we might be able to take a brief family getaway while causing the least amount of disruption to his routine?

As Larry James, a Montreal father of a child with pervasive developmental disorder, notes, “leaving the security of home to a new place can be off-putting for a child with autism and his or her family. All the preparation may seem a bit daunting, but it pays to plan ahead, because you’ll reap the benefits of a less stressful trip that may actually turn out to be quite enjoyable.”

The following tips may help you to plan for your trip and maintain the consistency that your child is accustomed to:

- How you prepare your child emotionally depends on his

You may want to compose a social story for your child which describes the journey you are about to embark on and highlights the fact that you will be returning home.

age and ability level. In order to smooth the transition from one environment to another, you may want to compose a social story¹ for your child which describes the journey you are about to embark on and high-



lights the fact that you will be returning home.

- Taking a short trip is recommended before attempting long voyages.
- Airports and train stations are areas that involve lots of waiting, noise and sensory overload that can be overwhelming for “mainstream” children, all the more so for those who have issues around sensory integration.
- If you are traveling by plane, call the airlines as far in advance as you can and tell them you will be traveling with someone who has special needs. You may wish to explain about your child’s needs and some of the behaviours that may affect other travelers. You may also request that assistance be provided to help you with your child and luggage to get to the departure gate and ask that assistants meet you at the airplane upon arrival.
- Think of your child’s daily routine and the items that bring him comfort and security and bring them along to make him feel more

¹ Defined by Carol Gray in 1991, social stories describe a situation, skill, or concept in terms of relevant social cues, perspectives and common responses in a specifically defined style and format, that incorporates pictures or graphics. For directives on how to compose a social story, visit www.thegraycenter.org/socialstorywhat.cfm

Adapted Travel

at home. Your list might include a favourite toy, book, stuffed animal, blanket, pillowcase and even pajamas, bath soap and food that are familiar.

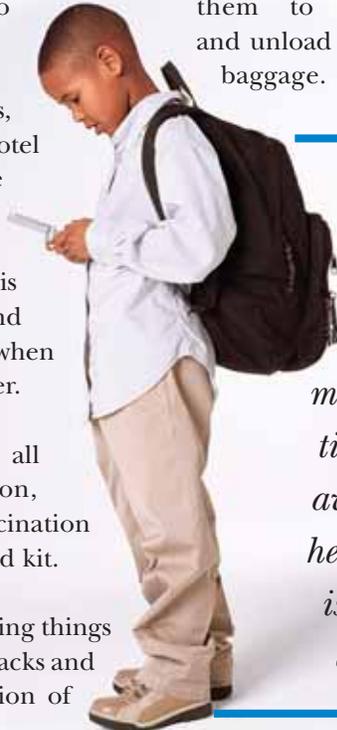
- When staying in a hotel, it is a good idea to call ahead and ask for a room in a quiet area of the hotel, especially if there is some kind of party taking place there.

- You may wish to explain your child's temperament and reactions to relatives, friends and even hotel staff that may not be familiar with your child in order to sensitize them to his or her behaviour and gain their support when relating to him or her.

- Make sure to bring all necessary medication, hospital cards, vaccination records and a first-aid kit.

- Plan activities and bring things like a DVD player, snacks and music for the duration of the travel.

- As much as possible, try to maintain your child's meal, bed and bath-time routines while away, so that his or her general structure is not disrupted to any great degree.



or at a ticket counter. In most locations VIA has personnel who can escort individuals to the platform, assist them with boarding and disembarking from the train and help them to load and unload their baggage. You



As much as possible, try to maintain your child's meal, bed and bath-time routines while away, so that his or her general structure is not disrupted to any great degree.

can benefit from priority boarding five minutes before regular boarding commences. To take advantage of these services, you must identify yourself to VIA personnel upon arrival at the station.

There is no additional fee to travel with a guide dog. To make sure both you and your animal are comfortable, VIA will provide you with a second seat free of charge in both its Comfort (economy) or VIA 1 classes. Your guide dog must wear a special harness with a "U" shaped handle at all times. It must be noted, however, that VIA's accommodation to animals applies strictly to service animals such as guide dogs and not to pets, who must travel in the baggage car.

3. Our 18-year-old daughter has hearing impairments and I am increasingly frustrated by how little the travel industry does to accommodate people like her.

The Canadian Association for the Deaf (CAD) agrees with you. Many

2. My son has visual impairments and we plan to take our first family trip by train. What are the type of things we should be aware about as we prepare for it?

Via Rail (www.viarail.ca) recommends that clients with visual impairments find out about the services available to them by contacting one of their sales agents by telephone

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airports do not use adequate signage (e.g. electronic display boards) to announce boarding times and flight numbers. Some airports have the signage, but neglect to utilize it in prominent locations where it would be of use to travelers in need of flight and boarding information. The CAD believes that all transportation terminals should offer visual displays of information and announcements.

Another issue of concern raised by the CAD is the fact that safety videos on airplanes are not captioned. While open captioning on all safety videos would be wonderful, even more ideal would be for the videos to be created in a style that requires no languages at all, so that every passenger could understand them regardless of their hearing abilities or linguistic group. Less of a priority although equally frustrating is the lack of captioning on all in-flight movies and television shows.

The CAD also believes that all transportation employees (such as flight attendants and train conductors) should be trained to work with travelers who are deaf in emergency situations.

In terms of sleeping accommodations, the CAD insists that hotels



Even more ideal would be for the videos to be created in a style that requires no languages at all, so that every passenger could understand them regardless of their hearing abilities or linguistic group.

across Canada should provide full and equal accessibility to all guests with hearing impairments. TTYs², caption decoders (boxes that provide captions on televisions) and

illuminated fire alarms and doorbells should also be available at all hotels for guests who are deaf. Another problem with hotel accessibility is that the switchboards sometimes do not permit direct TTY calls to Message Relay Service (an operator service that allows people who are deaf, hard of hearing, speech-impaired and deaf and blind to place calls to standard telephone users). The switchboards are set up to process outgoing calls on a local or long-distance basis only, with standard area codes included in the dial-up. The CAD has been repeating all of these points for years and continues to fight for rightful access on a case-by-case basis through the Canadian Transportation Agency or the Canadian Human Rights Commission. If you would like to voice your concern about the travel industry's lack of accommodation for people with hearing impairments, contact the CAD at info@cad.ca.

² A TTY or Tele Typewriter is a device that uses text instead of voice to communicate via telephone lines.

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Mike Cohen is a Montreal writer, communications and marketing specialist for the English Montreal School Board and a Côte Saint-Luc city councilor. Contact Mike at adaptedtravel@exceptionalfamily.ca See his website at www.mikecohen.ca and his travel tips at www.sandboxworld.com.

Sexuality in the Schoolyard

EF presents the final article in an exclusive three-part series on Birds, Bees and Boundaries with exceptional youth



by DAVE HINGSBURGER

School. If you are the parent of a child with a disability, that one word evokes so many emotions. You probably have fought with teachers and clinical teams, had angry disputes with principals and professionals, done battle with both bigots and boards. And all for your child to get an education. To go to school with others. To have typical experiences. To have the opportunity to learn and grow in a natural environment. All these goals are good, and all the battles have been worth fighting.

However, when you were thinking about those “typical experiences,” chances are you were thinking about such activities as going to class, playing in the gym with friends, or socializing during lunchtime; not experiences relating to sex, right? For anyone shaking his or her head

For anyone shaking his or her head and thinking that sex has no place in school, you may want to reflect on the soap opera dramas that played out in the hallways of your own school.

and thinking that sex has no place in school, you may want to reflect on the soap opera dramas that played out in the hallways of your *own* school. Remember the “Tracy dumped Steve because Steve kissed Karen when Karen was breaking up with Helen show” that took place every time the

bell rang to mark class change or lunch break? Well, it happens in your kid’s school too. Even your exceptional kid’s school.

When kids without disabilities interact with each other, they follow a very fine but very firm set of social rules that are often invisible to kids with cognitive challenges. When exceptional kids see their peers kissing, behaving provocatively and staging “passion plays” in the hallways, they often end up getting very mixed messages. They tend to believe that the “mainstream” kids welcome anyone into the game and that all the touch rules that they have learned are no longer applicable.

Nothing can be further from the truth. For although these teens are testing limits, they are also setting

them down very firmly – deciding *who* can play and *how* the game can be played. Only those who are in “the club” are allowed to play. On the other hand, a young boy with Down syndrome mistakenly entering



in the game and engaging in the exact behavior he has just witnessed can get into very serious trouble.

As you think about your child’s new school year, consider strongly how you want that year to run. What do you want your child to experience? You need to be very careful here. As your child grows into a teenager, sexuality becomes a greater issue of concern. Sure it’s something to be celebrated as part of normal growth and development, but it’s also an area that can cause tremendous difficulty for your child. A single slip or mistake can demonize your son as an offender or as dangerous, when all he was trying to do was establish himself as a sexual equal with the other boys. Similarly, a single error can result in your daughter’s victimization when she was merely attempting to be “sexy” like the other girls.

My point in highlighting these facts is not to suggest that you lock up your children. Rather, it is to emphasize that all of your concerns are legitimate.

While mainstreaming and inclusion are great for your child in so many

ways, there are also real social/sexual dangers to be aware of when your child attends a mainstream school. The following proactive suggestions may help you to prepare your child for life as a teenager at school.

You may find that the



Talk about the dating and the kissing and the hand-holding. Don’t tell your child that those activities are not for “him.”

more your child is prepared, the more relaxed you will be about your child’s interactions with others.

Boundaries, boundaries, boundaries. I know I repeat myself on this issue, but boundaries will be the most important social skill you teach your child. Now that summer has come to an end, you need to brush up on the training you’ve given your child around boundaries. Remember that your

child doesn’t learn the same way other kids do, so teach boundaries in a variety of ways:

- A) Talk to your child about the concept of boundaries.
- B) Model them in your daily behaviour.
- C) Have your child role-play them for you in order to ensure that he or she understands the concept.
- D) When you see someone applying good boundaries in the community or on television, comment on it and emphasize their actions positively.
- E) Practice boundaries continually.

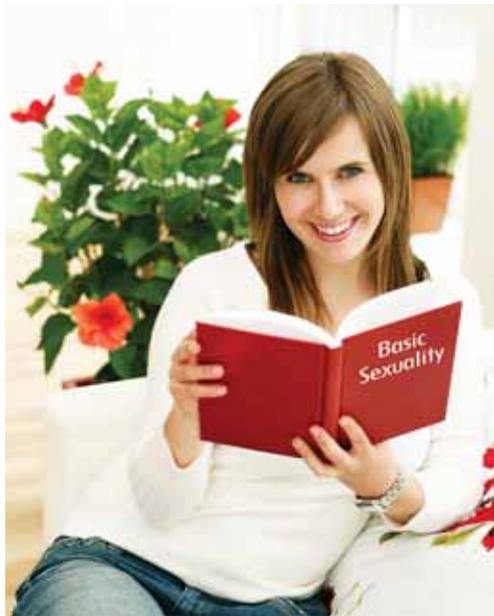
Inform your child in advance about what he or she will be seeing in school. Talk about the dating and the kissing and the hand-holding. Don’t tell your child that those activities are not for “him” – that will just drive relationships and desires underground and as a result your child may begin to hide things from you. It would be tragic for your child to lose you as a resource. Explain that the people engaging in these activities have a mutual **agreement** that this behavior is okay. Some of them are boyfriends and girlfriends, others are just beginning dating, but the important thing is that these boys and girls have agreed to this kind of interaction. Emphasize the importance of consent between two people. Remind your child about the private parts of the body and that no one can touch his, hers or someone else’s without permission. This is the basis of

“consent.” Expand this discussion by applying the concept of consent to other social behaviors like kissing and hand-holding.

Debrief daily in order to keep yourself up-to-date on how your child is navigating adolescence.

Ask your child to tell you about what the other kids are doing in school. Observe your child during the time that you first see each other after a school day. Notice if he or she is withdrawing, is overly happy, or exhibiting any emotional changes that are out of the ordinary. Sit down and talk about what’s going on. Make note of any new name you hear appearing in the course of your child’s dialogue. Does your child seem to be developing a crush of some kind? Remember to be a confidante not an inquisitor so that your child will feel that you are approachable and non-judgmental.

Inform yourself about sex. Believe it or not, what you know about sex from sex education classes in school has mostly been forgotten. Adults are not the best resources



to answer kids’ questions. Get a book or two from the library on basic sexuality in preparation to answer questions. If a question arises that really throws you and you feel that you can’t answer without becoming extremely embarrassed or upset, say, “Let me check on that for you” and let the issue rest for a day or two while you catch your breath. One mom was shocked, for example, when her child recently approached her with, “How do you know if you are gay?” She managed to breathe and answered calmly and soon learned

that her son was asking because a boy at school had just come out. Had her son actually been gay, however, a quick and negative response could have destroyed the relationship between them.

Believe it or not, what you know about sex from sex education classes in school has mostly been forgotten. Adults are not the best resources to answer kids’ questions.

Find out whether the school offers Sex Education and Relationship Training and whether the training has been adapted for exceptional students. The Family Life and Sexual Health Curriculum from Seattle, developed for adolescents in school, is a very good example of a curriculum that teaches the right things at the right times to

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In support of this initiative, Miriam Foundation, our fundraising arm, launched a national quarterly publication called Exceptional Family in the

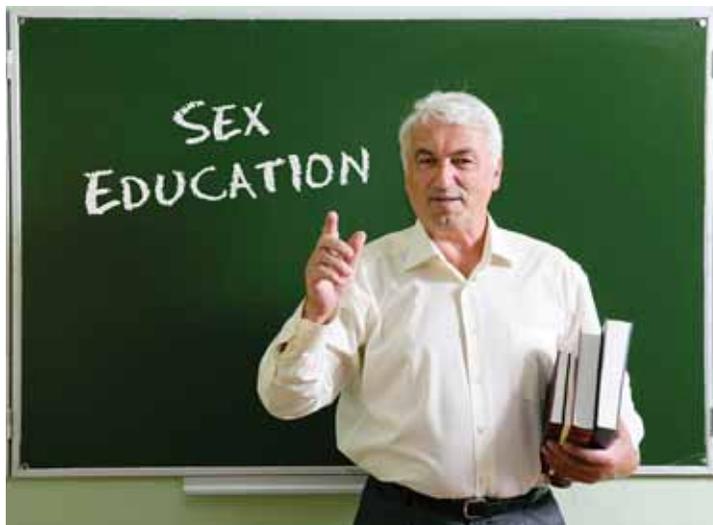
fall of 2005 to serve as a public resource for exceptional individuals and their families residing across Canada.

For more information on how you can support such programs, contact the Miriam Foundation at (514) 345-1300 or visit our web site - www.miriamfoundation.ca.



kids in school. This program, though based on the curriculum for typical children, is adapted for students with disabilities. Check out local organizations that serve people with disabilities and find out which offer such programs. Although your child likely learned about social skills, boundaries, privacy and the like during his or her formative years in an informal setting, a more formal program is necessary for teenagers. And sorry to say, it's best that parents do not teach this curriculum to their own children.

Talk to the school. Tell the school that you'd like your child to be a bit more supervised during breaks and lunch period to ensure that he or she is doing well. It's also important to begin a discussion about your desire to exchange information. Tell the educators involved with your child that if he or she seems to be developing crushes or attachments at school, you'd like to be informed. Let them know that your intent is not to punish or prevent your child from having friendships and relationships, but rather to support



The teen years are difficult for all parents and all parents have to go through the experience of watching their babies become teenagers.

your son or daughter's feelings in the home environment.

Talk to other parents. While no one can really understand the concerns you are facing around

your child's interest in sexuality, another parent who's been there can surely offer some perspective. A parent of an exceptional child who is married, for example, would be an ideal person to share ways in which he or she handled his or her teen years and relationships. It's nice to have someone to talk to freely without feeling like you have to watch your

words, as is sometimes the case with teachers and professionals. Talking to a fellow exceptional parent will also make you feel supported and will help you to feel less alone as you go through this challenging stage.

While the list might seem daunting, you can take comfort in knowing that there is little on this list that wouldn't be applicable to *all* parents of adolescents. The teen years are difficult for all parents and all parents have to go through the experience of watching their babies become teenagers. The good news is that adulthood is around the corner and before you know it this stage will just be a thing of the past. In the meantime, by being careful and prepared, your children may end up with fewer bruises while you may just succeed in getting through it without an ulcer. ■

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

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Dave Hingsburger is an internationally renowned speaker and writer on disability issues. He is also the clinical manager for Vita Community Living Services. You can find out more about Dave's books from www.diverse-city.com and read more of Dave's writing at davehingsburger.blogspot.com.

Inspiration

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

*I think at the end of the day,
if you have talent and you stand above the rest,
there is nothing in the world that can stop you.*

- Deanne Bray



Photo: Joseph Viles

Deanne Bray

Television, theatre and film star, DVD producer, person who is deaf, advocate, teacher of math and science, former host of “Caption This” – a nationally-syndicated TV show, founder of “The Little Bookworm Club” literacy program for children who are deaf or have hearing impairments, wife, mother



If Only Children Came With Instructions

Behaviour Management Part One: The Evaluation and Planning Phase

We need to take lessons and acquire a license in order to drive a car. We need to earn a diploma and master a degree in order to be proficient in most fields and careers. Yet there are neither manuals nor set curricula to teach us how to raise our children - which, although immeasurably rewarding, is also the most challenging job of all. While the nature of quandaries around child-rearing may change from "my three-year-old won't sleep in her own bed" to "my son wants to pierce his ear," behaviour management issues are bound to come up repeatedly over time.

Rather than refer to "mainstream" parenting books which don't necessarily consider the needs of children with special needs, exceptional parents stand more to gain from seeking the input of a professional who can create an *individualized* behaviour management program geared exclusively around their child and family's particular needs.

Frequently, when parents make an appointment in my clinic related to difficult behaviours at home or at school, they arrive with very high hopes looking for immediate answers. During our first meeting, they list their concerns and ask me to tell them what to do. Some seem surprised when I say that I must



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meet and evaluate their child before *we* can begin to design and implement their "manual." I emphasize the "we" as the input of parents and teachers is an integral part of the process. The process in question requires that you keep a log of your child's behaviours and your responses

to them for the next couple of weeks. So grab a pen and let's get to work!

Step One: Evaluate the Antecedents (Causes) and Behaviours

Observe and record your child's behaviours. Try to determine what causes them and which of your responses appear to work most successfully. Pay attention to such factors as the time of day, whether he is hungry or if she is behaving in a certain way because of hypersensitivity to a given trigger. It is also important to evaluate whether behaviours are intentional or part of the child's temperament and/or syndrome.

Some exceptional children, for example, may be cognitively incapable of conceptualizing "right" and "wrong." They may be completely unaware that they are acting inappropriately and out of touch with their own feelings. Additionally, they may be incapable of making cause and effect connections and therefore unable to control their behaviours, or act impulsively without thinking. Intrinsic sources of motivation would therefore be meaningless to them. A tangible reward may be the only means of motivating and guiding such children to meet set goals. This one factor will make

STARTING YOUR LOG: A Few Practical Suggestions

1. Make a list of all of your child's positive characteristics and/or behaviours.
2. Make a list of all of your child's negative characteristics and/or behaviours.
3. Rate the second list (of negative characteristics) by severity from 1-3.

1 = I find the behaviour very disturbing; can't tolerate it

2 = I would like to change it, but it's not urgent

3 = I find this behaviour the least disturbing, but would like to work on it eventually.

Keep a journal for two weeks in which you observe the ABC's.

A = Antecedent
B = Behaviour
C = Consequence

Look for trends in you child's behaviours. For example, list the day and time of the antecedents and behaviours.

EXAMPLE

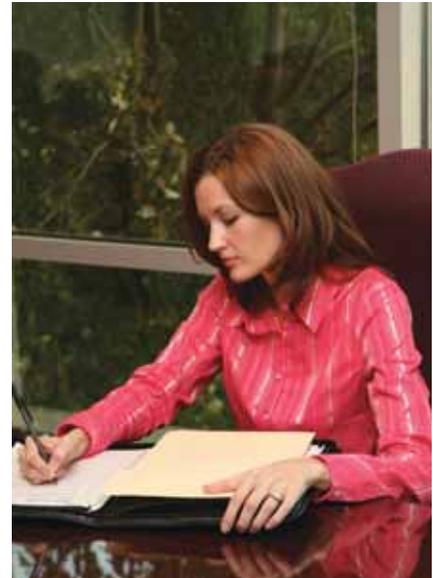
DAY/TIME	Tuesday Lunch
A	Gave her carrots
B	Threw her food on the floor
C	I yelled and she cried
RESULTS	Everyone was upset
POSSIBLE TRENDS	1. Could be time of day 2. Could be type of food

5. Next, look at the consequences and their potential impact on your child.
6. Try changing the antecedent to solve the problem (e.g. feed her another vegetable, or feed her earlier).

If changing the antecedent is ineffective, work on a consequence (i.e. remove her from the kitchen or give her a sticker for not throwing her food).

Remember to:

- Think of your child as an individual with a unique temperament, likes and dislikes.
- Consider your child's level of development.
- Once you decide on removing an antecedent or modifying the consequences, be **consistent** in your approach.



*I often hear parents
and teachers say
"I don't know what to do;
he just hits people for
absolutely no reason."
As I always explain,
there is a reason;
we have to dig deeper
to find it.*

a huge difference in whether a behaviour management program has a chance of working.

Suppose, for example, that Marla throws tantrums and hides under the table at her daycare only during activities that involve pasting. Given that her behaviour is isolated, we might speculate that perhaps Marla is hypersensitive to the texture of glue on her hands. Marla's tactile hypersensitivity constitutes the antecedent.

Sometimes it's not that easy to figure out the antecedents especially if your child is nonverbal or has difficulties expressing him or herself. I often hear parents and teachers say "I don't know what to do; he just

hits people for absolutely no reason." As I always explain, there is a reason; we have to dig deeper to find it.

Step Two: *Try to Change the Antecedents*

Once the antecedents and behaviours have been identified and analyzed, the next step is to try to change the antecedent.

In the case of an impulsive child unable to control his or her behaviour or a child who manifests behaviour as a result of a syndrome, numerous positive treatment options can be attempted, which may turn out to be far more effective than punishment in reaching desired goals.

In Marla's case, she may have had one of many disorders which include sensory integration dysfunction. Instead of sending her in "time out," for example, her teachers might try to change the antecedent by allowing her to do another activity while the others are pasting or encourage her to wear latex gloves while handling glue. Marla could also be taught to express her discomfort by practicing such phrases as, "this feels funny, I don't want to touch it." Finally, a gradual desensitization program can be

designed to help Marla overcome her discomfort to the point where she ultimately participates fully in the activity.

Step Three: *Evaluate and Select Potential Consequences*

After altering the antecedent, desirable behaviours can be reinforced and achieved by implementing either positive or negative consequences.

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If a child is intentionally behaving badly, negative consequences may help to reduce certain behaviours while positive reinforcement will certainly help in increasing positive ones. The one point that is important to keep in mind, however, is

that if you are enforcing a punishment, the consequence should be inherently negative. I often think of Sarah, a child in kindergarten, whose behaviour was labelled "non-compliant, overly active and annoying" to the other children. Her parents and teachers created a daily behaviour chart which required that Sarah earn two happy faces in order to be able to engage in a "special" activity with her mother after school. If Sarah's chart was marked with sad faces, however, she would have to spend 30 minutes in her room upon arrival from school.

Sarah's parents consulted me as her behaviours were getting worse, despite the fact that the behaviour chart was being implemented daily. When I asked Sarah about her chart, she stated, "I'm tired after school, so I behave badly and then I can rest in my room." The problem was resolved, in part, by giving Sarah a chance to rest once she returned home, coupled by a reward after a successful day. (Of course this was one small part of a greater behavioural intervention.)

Once you have gone through all three steps, you will be ready to begin writing the behaviour management "manual" for your child - a process we will explore next issue. Good luck! ■

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or
- C) A one-year subscription to *Exceptional Family*, Canada's Resource Magazine for Parents of Exceptional Children

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Dr. Harriet Greenstone is a psychologist and the Director of Centre MDC, a multidisciplinary care centre specializing in children, adolescents, 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.

Insights

A compilation of upcoming conferences and training sessions of interest

October 25 – 26

Asperger Manitoba Inc. 1st Annual Conference

Asperger Manitoba Inc. presents its 1st Annual Conference - "Breaking Through" featuring Dr. Kevin Stoddart and seven other presenters on a variety of topics, suitable for parents and professionals. Canada Inn Polo Park, Winnipeg, MB. AMI member: \$80 Non-member: \$100 Professionals: \$90 for 1 day or \$150 for 2 days. Individuals with Asperger Syndrome: Free. Information: (204) 947-9449 or www.asperger-manitoba.ca or info@asperger-manitoba.ca

October 30

Fetal Alcohol Spectrum Disorder (FASD) Conference

Learn how FASD manifests, where to get a diagnosis and how to support people with FASD at home,

school and work. Newmarket, ON \$50. Information and registration: Amanda Lewis: (905) 773-4323 or alewis@bluehillsschildandfamily.ca.

November 8– 9

1st Symposium on Autism and Developmental Disabilities

The Abe Gold Learning and Research Centre will be hosting its 1st Symposium on Autism and Developmental Disabilities on issues including education, intervention, medical diagnosis and research. Four keynote speakers will present over the two-day period: Dr. Robert Schultz, Dr. Jeanette McAfee, Dr. Helen Tager Flusberg and Dr. Kathleen Quill. Simultaneous French translation available. Twenty breakout sessions will be offered in both official languages. The symposium will also feature a designated area for the

presentation of research and information related to Autism and Developmental Disabilities as well as a large vendor exhibition area. Le Chateau Royal, 3500 boul. Souvenir, Laval, QC. Students/Parents/Family Members/Participants with a disability: \$175, Professionals: \$375. Information: (514) 345-8330 ext. 319 or visit www.goldlearningcentre.com.

November 9

The 11th Annual Active Living Conference

The hosts and sponsors of this year's conference are pleased to invite you to "Directions in Diversity ~ An Introduction to Inclusion" – a full day of dynamic and interactive learning facilitated by experts on inclusion and diversity. This conference will be of great value to consumers, students and professionals interested in active living opportunities for people of varied abilities. Variety Village, 3701 Danforth Avenue, Scarborough ON. Registration: \$30. Information: Archie Allison: (416)-699-7167, ext. 236, TTY (416)-699-8147 or aallison@varietyvillage.on.ca

**If you're not aware of the following fact, here's
one more reason to check out our web site**

Of the 181,000 exceptional children in Canada, 57.4 percent of them experience a mild to moderate disability, while 42.6 percent have a severe or very severe disability, according to Statistics Canada. In Quebec, the disability rate for children ages five through 14 is almost double the national average. What parents should be aware of is that many thousands of Canadian children diagnosed as having mild cognitive impairments can become fairly self-sufficient and, in some cases, live independently with community and social support from institutions such as Miriam Foundation.



Check us out! **Exceptional Family** –
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Click on the link **Our
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To publicize an upcoming conference or training session of interest **FREE** of charge, contact us at feedback@exceptionalfamily.ca. All information will be subject to the discretion of the editor and publisher.

ABILITY PLUS THERAPY

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Contact: Roberta Neves, MPT
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Laura Joslin (Cheyne's Mom)
email: abilitytherapy@aol.com
www.abilityplustherapy.com

Cheyne was prematurely born at 26 weeks, weighing only 1 pound 10 ounces. He was first diagnosed with Spastic Quadripareisis Cerebral Palsy at 18 months old. At 6 yrs. old, he had little to no mobility, even though he received therapy at home 3 days a week. When Cheyne was 7 yrs. old, he began Intensive Therapy and the results were dramatic. At 8 yrs. he was using a rolling walker, at 10 yrs. he started using two canes. Now at the age of 15, he continues to use canes for long distances and walks with minimal assistance for short distances. Cheyne has been re-diagnosed with Spastic Diplegia and continues to work towards his goal of independent walking. A neurologist once told us Cheyne would never walk. We had no idea of what Cheyne would accomplish until we found Intensive Therapy.

"It Changed my Life"
Cheyne Joslin



The Wave of Change, Combining Intensive Physical / Suit Therapy with HBOT makes all the difference in our Children

With Cerebral Palsy and Traumatic Brain Injury, a large area of the brain surrounding the damaged site becomes dormant due to decreased blood flow thus reducing oxygen flow to the area. Studies have shown that HBOT "wakes up" the dormant cells promoting the following outcomes:

- Decreased spasticity
- Improved gross and fine motor skills
- Improved speech/communication
- Improved vision and hearing
- Improved cognition

Jeff Bradstreet, M.D., F.A.A.F.P.
Medical Director / Founder

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