

# EXCEPTIONAL FAMILY

CANADA'S RESOURCE MAGAZINE FOR PARENTS OF EXCEPTIONAL CHILDREN

Vol. 1 No. 4  
Summer 2006

## Yoga-Based Therapy

Holistic exercise offers multiple benefits

## Is ADHD Over-Diagnosed?

An in-depth look  
at Attention Deficit  
Hyperactivity Disorder

## In Focus

The "special needs"  
of exceptional siblings

## What is so Fragile about Fragile X Syndrome?

Common features and  
significant differences  
between autism and  
Fragile X Syndrome

## Equine Therapy

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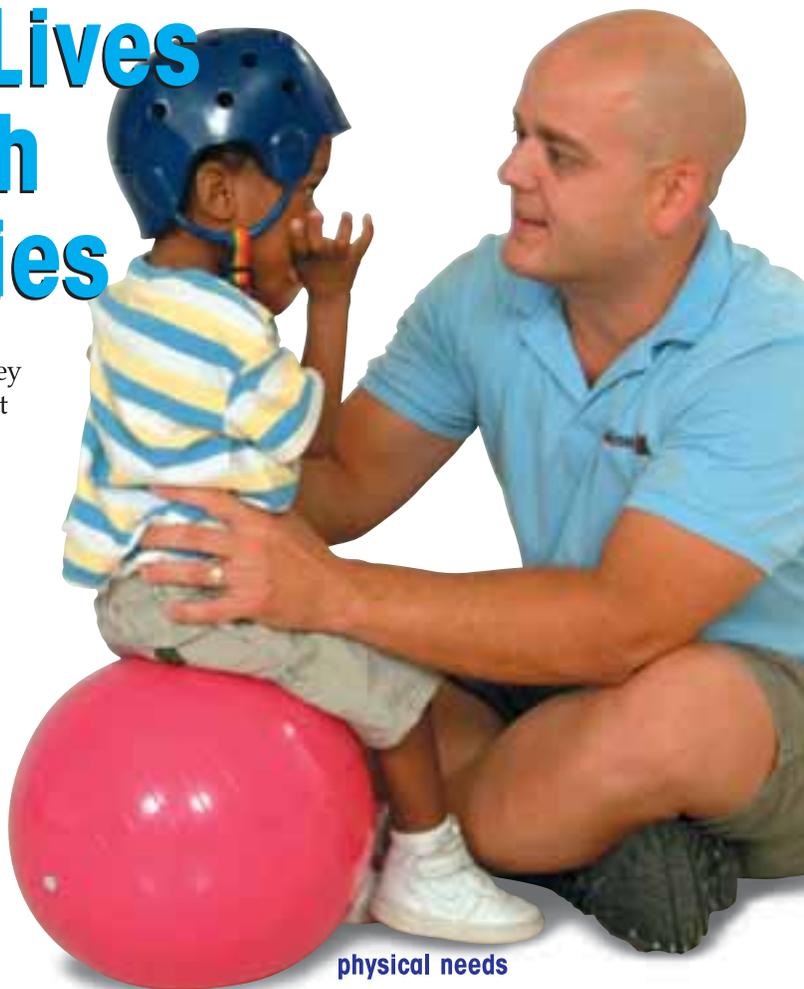
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# EXCEPTIONAL FAMILY

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## FROM THE EDITOR

### Seeing Is Believing



Over the past year, *EF* has shone the spotlight on three exceptional individuals who have soared above overwhelming challenges and achieved more in their relatively young adult lives than many “mainstream” people ever accomplish in a lifetime: Andrea Bocelli, Marlee Matlin and Sam Sullivan are all remarkable people who truly personify the word “Inspiration.”

On a personal level, however, none have moved me as much as Ryan Knighton, the star of this issue’s *Inspiration* feature. Knighton is the author of *Cockeyed*, a captivating new memoir that delves into his childhood and fifteen-year progressive loss of vision as a consequence of a condition called *retinitis pigmentosa*. Knighton is also a published poet and co-founder of a magazine, a lecturer, a college teacher, a producer and performer of radio monologues and documentaries, a former editor and a freelance writer. A frequent contributor to *The Globe and Mail*, Knighton’s pieces are succinct, articulate, witty and entertaining. In short, they are masterful works of art.

While all of our *Inspiration* personalities are each remarkable in their own right, Knighton’s accomplishments resonate with me particularly because of our mutual interest in journalism and writing. Reading and writing form the essence of my own job as a writer and editor. Without these capabilities, I cannot imagine being able to perform my job as a journalist successfully. Which is why I view Knighton’s ability to produce such brilliant pieces without writing and visually-revising them as such a spectacular feat.

A 2001 article in *Advance News* (*Blind Teacher Sees Poetic Success*) described Knighton as a person who does not want to be seen as a ‘triumph story’ and highlighted his discomfort around the fact that “people with handicaps are often portrayed as being heroic for simply achieving goals that are considered normal for people without disabilities.”

While Knighton’s assertion is extremely valid, the sheer magnitude of his accomplishments relative to those of many “normal” people already renders him outstanding, blindness aside. When one considers then, that Knighton has realized multiple dreams in spite of his disability, his accomplishments become all the more laudable.

Knighton is a man, who, by all standards, is exceptional. He is a man who has taken vision to a whole new level; for Knighton, the ability to see stems not from his eyes but from his belief in himself and his own potential. This is what makes Knighton a hero.

This issue of *EF* marks the fourth and final installment of Volume One. We hope you derived as much pleasure reading our first four issues, as we did in presenting them! Stay tuned for Volume Two this Fall, which promises to be every bit as exciting, informative and of course, inspirational.

Have a wonderful summer!

Aviva Engel

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# EQUINE THERAPY

## gives new meaning to horseplay

by AVIVA ENGEL

**P**hysiotherapy. Occupational therapy. Speech therapy. Behavior therapy. If you're a parent of an exceptional child, chances are your son or daughter receives at least one of these rehabilitative treatments. Recently, a rather unique kind of therapy has been gaining popularity among exceptional families who are discovering its wide-ranging benefits. It's called equine therapy, and proponents of this emerging field tout its wide-ranging benefits.

Equine therapy, or therapeutic riding as it is more commonly known, is a treatment in which horses are used as a medium to enhance clients' physical, cognitive, emotional and social strengths and abilities. While it is not recommended as a substitute for any one therapy in particular, it shares many of the conventional ones' same advantages. Besides equine therapy's allure as an outdoor activity, which is novel for those typically treated in clinical settings, its adaptability to individual needs and objectives makes it accessible to a broad range of people with disabilities. These include Down syndrome,



*Yvonne Tannahill, 12, rides Bijoux, accompanied by her mother Carole Ness, who is a Side Walker*

---

*Besides equine therapy's allure as an outdoor activity, its adaptability to individual needs and objectives makes it accessible to a broad range of people with disabilities.*

---

autism, Rett syndrome<sup>1</sup>, ADHD, Prader Willi syndrome<sup>2</sup>, developmental delays, visual impairments, cerebral palsy, spina bifida, neuro-

muscular disorders and disabilities related to brain or spinal cord injuries and amputations. Horseback riding's general popularity as a recreational pastime makes equine therapy all the more appealing as an inclusionary activity.

### Physical, cognitive and emotional benefits

Anyone who's ever ridden a horse knows that good coordination, balance, and strong back and trunk muscles are crucial to any successful riding experience. In addition to exercising and toning muscles in a manner that closely simulates walking, equine therapy stimulates riders' circulatory systems, increases their flexibility and improves their postures, balance and hand-eye coordination. It also reduces muscle spasticity.

Getting a horse to respond to commands also requires good



<sup>1</sup> Rett syndrome is a genetic disorder marked by progressive neurological deterioration, seizures and cognitive impairment that principally affects females.

<sup>2</sup> Prader Willi syndrome is a genetic syndrome characterized by short stature, developmental delays and mild to moderate mental retardation, excessive eating and obesity, and hypogonadism.

communication skills and concentration. For riders with cognitive deficits, equine therapy encourages language development, increases attention span and aids sequential and cognitive thinking. Finally, it enhances self-esteem, encourages independence and social-skill building and fosters friendships between riders and their instructors and horses.



“Horses are extremely sensitive to all of our movements and communication methods, whether verbal or non-verbal.” said Debbie Wilson, Program Coordinator of the Lucky Harvest Therapeutic Riding Center in Herdman, Quebec. “Children who have difficulty with concentration can be taught how to make their horse walk, or stop or turn. In order to successfully execute these actions, riders first have to grasp the practical part of the lesson, focus their attention, coordinate their own bodies to move the animal and use language to stop it. It’s very rewarding for children to make their animal stop by themselves.”



*In circle: Émile Cardin Lalonde, age 4. Above: Yvonne Tannahill several years ago with Chauncey the cat and two volunteer Side Walkers.*

*“It’s very rewarding for children to make their animal stop by themselves.”*

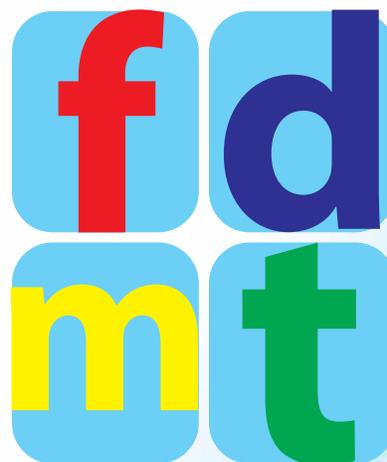
Montreal in order to attend weekly riding sessions, the serene setting, beautiful foliage and chance to spot wild animals like rabbits, chipmunks and deer offers them a welcome break from the flurry of urban living. “Most parents can never provide this kind of an opportunity for their child in the city, beyond the monotony of hospital therapy,” said Wilson. “Coming out here is a real respite and relief for many families. It’s a change of pace and scenery. They really appreciate that time to get away from everything.”

The center also has an indoor arena that is used in inclement weather and during the cold winter months. While each session is one-hour long, riders are encouraged to visit the stable before they ride to socialize with the volunteers and interact with their horses. During the actual 45-minute riding lesson, instructors often incorporate balls, hula hoops and cones and devise games and obstacle courses designed to hone riders’ fine-motor skills, balance, hand-eye coordination, and direction-awareness. Once riders dismount, they’re invited to assist in

### An opportunity for respite

As the first certified riding center in Quebec, Lucky Harvest is located on a rural farm that spans three acres of land adjoined by another 29 acres of trails in the woods.

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the untacking and grooming of their horses and reward the animals with treats for their hard work.

And the horses are hard workers indeed. In addition to the hours that each puts in daily, all horses at Lucky Harvest undergo between two and three months of training before people with disabilities can ride them. During that time, the animals are introduced to mounting ramps<sup>3</sup> and wheelchairs and are even bumped with the chairs a couple of times in order to become acquainted with the sensation, should a similar occurrence happen unintentionally during an actual session. Similarly, the instructors roll balls on the animals' ears, noses and backs, in order to prepare them for the possibility of accidentally being struck by one during a game. In preparation for the mounting and dismounting of riders with physical disabilities, the horses also learn to stand still for ten minutes at a time and get accustomed to being surrounded by a number of people.

"When you're working with exceptional children, [some] tend to be very loud," said Wilson. "They may clap and get excited very easily, kick or yell to express their happiness, and this could be hard on a horse's back. We want to make sure that the horses are going to be comfortable with any type of scenario that could

happen and that we know how they are going to respond."

### Noticeable improvements

For Carole Ness and Glen Tannahill, whose daughter Yvonne has Rett syndrome, there is a sense of comfort in knowing that the horses are well



*Clockwise: Paul Michael Laxton, 5, with his instructor, Julie, and father, Gary. Right photo: Régis Carrière, 25, with instructor Isabelle Tremblay and leader Debbie Wilson work on balance, and Émile Lalonde, 4, brushes his horse with the help of instructor Annika Voeltz.*

trained to handle any eventuality. At twelve years old, Yvonne is a veteran horseback rider, having taken equine therapy at Lucky Harvest since she was two years old - the age at which her diagnosis was confirmed. At first, Yvonne was physically strong enough to stand independently in the horse's stirrups while riding, but because of her

degenerative condition, Yvonne is no longer able to bear weight on her legs and requires the help of four adults to transfer from her wheelchair onto her horse. Yvonne has scoliosis<sup>4</sup> and epilepsy and while she is non-verbal, she understands a tremendous amount and is able to communicate with those around her.

"Yvonne speaks volumes with her eyes," said Ness, who accompanies her daughter as a Side Walker<sup>5</sup> on all of her lessons. "She also makes some choices with her eyes. It's evident by her reaction that she understands.



## Charting Early Developmental Steps in Fragile X Syndrome?

**Children play fun computer games and win prizes- at home or our specially designed lab!!**

The McGill University Fragile X Development lab is looking for boys 3-12 years old for a detailed study on the early development of counting and attention skills. Individual profiles of performance will be provided to allow families more appropriate access to educational resources and interventions.

**To receive more information or to book an appointment, please contact Julie Hanck: [Julie.Hanck@mcgill.ca](mailto:Julie.Hanck@mcgill.ca)**

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This project is supervised by Dr. Kim Cornish

<sup>3</sup> A mounting ramp is a ramp used to transfer a person from a wheelchair onto a horse.

<sup>4</sup> Scoliosis is a lateral curvature of the spine and rotation of the vertebrae.

<sup>5</sup> A "Side Walker" is someone who walks alongside the horse and supports the rider when necessary.



Yvonne during one of her sessions – accompanied by (L to R) Amanda Farquhar, Debbie Wilson and Ann Tessier.

She understands her favorite movies and laughs in the appropriate places. She laughs if something happens to someone in the family that she thinks is funny or sees someone she knows whom she hasn't seen in a while and she responds well to her school peers," said Ness.

6 Yvonne is integrated in a "mainstream" school.

As for her therapeutic riding sessions, "Yvonne just loves to get on a horse and go for a walk," said Ness. "Her eyes light up and she smiles and when we stop the horse, she usually rocks forward with her upper body - that's her cue for 'I want to walk'. When we walk she's still and she's happy, and if we stop to reposition her, she'll often rock again. Recently we had her trotting on a pony and she just loved it – she started to giggle and laugh. I think she likes speed," said Ness.

During her therapy sessions, Yvonne's instructor concentrates on extending and strengthening Yvonne's legs and helping her maintain her balance while riding. "Yvonne requires a tremendous amount of concentration in order to hold herself up on the horse - not to fall backwards or forwards or sideways," said Wilson. "It's an extreme challenge for her to use her back and abdominal muscles and keep her head straight. But this child is amazing – she can ride for about 40 minutes. If she loses her balance, she corrects herself and tries to pull herself back to the center of the animal."

In addition to improvements in Yvonne's balance and communication since she began riding, she has also gained control of involuntary physical movements often visible in people with Rett syndrome. "Girls with Rett syndrome tend to have a hand-wringing motion and they usually keep their hands tucked in close to their bodies," said Ness. "One of the things we were able to do through riding was to get Yvonne to bring her hands down and put them on the back of the horse. It's quite neat to see that she is able to focus and overcome that motion that is very hard to break."

Yvonne's parents are equally thrilled to see their daughter derive so much pleasure from an activity that is uniquely her own. "It's enjoyable to see how she reacts on the horse," said Tannahill. "It's her Brownies or ballet, or all those other things that she can't join," added Ness. "As a parent, it brings a real happiness to see her go to an activity that she obviously enjoys tremendously and to see her outside and interacting with an animal that she loves so much." ■

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# Is ADHD over-diagnosed?

*EF takes an in-depth look at the diagnosis and treatment of Attention Deficit Hyperactivity Disorder*

by RICHARD HABER, M.D.

In recent months, widespread coverage of Attention Deficit Hyperactivity Disorder (ADHD) in newspapers, magazines and on television has generated considerable hype and even some concern around the use of stimulant medications to treat this common condition. Amidst media reports that drugs such as Ritalin are being prescribed more and more frequently to children, some may wonder whether ADHD is over-diagnosed. Are kids being medicated more often? Additionally, is their increased exposure to video games, computers and action-packed TV and movies altering children's perceptions and causing them to become hyperactive?

All of these are legitimate questions, which we shall explore in greater depth. In this issue of *Exceptional Family*, I will concentrate on what a parent needs to know in order to arrive at an accurate diagnosis of ADHD. I will also elaborate upon academic and psychological treatment options and briefly introduce the role of stimulant medications.

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*ADHD is a real disorder with a biological basis. It is a condition in which there is a lack of neurotransmitters (brain chemicals) in those areas of the brain that help us focus on a task at hand...*

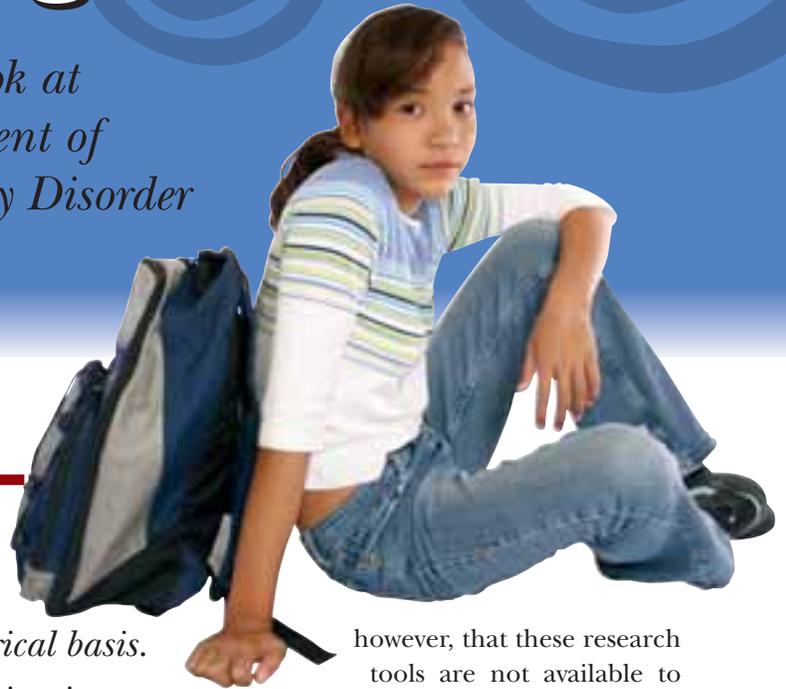
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ADHD is a real disorder with a biological basis. It is a condition in which there is a lack of neurotransmitters (brain chemicals) in those areas of the brain that help us focus on a task at hand and control our response to the thousands of stimuli we are bombarded with on a daily basis. The difference in the way the brain of a person with ADHD functions compared to a "mainstream" person can be visualized with sophisticated research tools such as PET scanners. It must be emphasized,

however, that these research tools are not available to patients in clinical practice; they are used by some researchers only.

Clearly, staying focused is a fundamental requisite of school-age children, whose very growth and academic performance are contingent on their ability to concentrate in a classroom setting. Consistent with this reality, a child's concentration and behavior problems are typically brought to his or her pediatrician's attention in the middle years of elementary school usually around Grades 3 or 4, when attention-based activities like reading are emphasized.

Often, parents' concerns are based on a teacher's suggestion that their child has the diagnosis, ("I think little Johnny needs to be on Ritalin!" or "Please consult a neurologist!") or the fact that their child's academic performance may not be up to par. It should be noted that although the



signs of ADHD are usually manifest at school age, the symptoms of the disorder have in fact been present from a very early age in many children.

If you suspect that your child may have ADHD, I urge you to be sure that a proper diagnosis has been made before considering any treatments, particularly medical ones. But first, it is important to educate yourself about the diagnostic criteria for ADHD:

The diagnosis of ADHD is essentially based on descriptors contained in the DSM-IV<sup>1</sup> published by the American Academy of Psychiatry. There are several classifications of ADHD:

1. ADHD, primarily inattentive type, i.e. without hyperactivity and impulsivity. This type is more frequently present in girls who may represent an under-diagnosed population because they tend not to be disruptive and impulsive.
2. ADHD, primarily hyperactive type, more frequently seen in boys
3. ADHD, mixed type, where both inattention and hyperactivity are present.

As children with ADHD grow, their symptoms of hyperactivity and impulsiveness may diminish while their inattentive features may become more prominent in school. Because ADHD is based on descriptions of the behavior found in the child, these descriptions must describe a *permanent* feature of a child's behavior, not a transient one related to anxiety or immaturity. Thus, a diagnosis is generally not made before the age of seven years to allow for maturation and in order to exclude other influences in the child's life which may contribute to his or her

instability, such as a major emotional upset caused by a relocation, divorce or death. In addition, the symptoms must be present in two or more settings, like home *and* school. It must also be established that the symptoms are not due to some other diagnosis such as pervasive developmental disorder, autism, mood disorders such as anxiety or depression,



a personality disorder, or other psychiatric or medical diagnoses.

The diagnostic criteria for inattention contained in the DSM-IV are six or more of the following present for at least six months and leading to some impairment of the child's expected academic performance:

1. Fails to pay close attention to details or makes careless mistakes in schoolwork, or other activities;
2. Difficulty sustaining attention in tasks or play activities;
3. Often does not seem to listen when spoken to directly;
4. Fails to follow through on instructions, homework etc.;

5. Disorganized;
6. Avoids or dislikes tasks requiring sustained attention;
7. Often forgets things or loses things necessary for a project or task;
8. Easily distracted by extraneous stimuli;
9. Forgetful in daily activities.

The diagnostic criteria for hyperactivity/impulsivity must have six or more of the following present for at least six months and to a degree that is impairing the child's life:

1. Often fidgets or squirms in a seat;
2. Often leaves seat in classroom when sitting is expected;
3. Often runs about inappropriately;
4. Difficulty in engaging in quiet play activities;
5. As if 'driven by a motor' or 'on the go';
6. Talks excessively;
7. Blurts out answers before a question is completed;
8. Difficulty awaiting turn;
9. Often interrupts or intrudes – butts into conversations or games.

In order to make a diagnosis of ADHD the child needs to be assessed by a psychologist who will administer a variety of neuropsychological tests<sup>2</sup> to ascertain the child's overall cognitive functioning, or IQ. The child's level of academic achievement is

1 Diagnostic and Statistical Manual of Mental Disorders, 4<sup>th</sup> Revision.

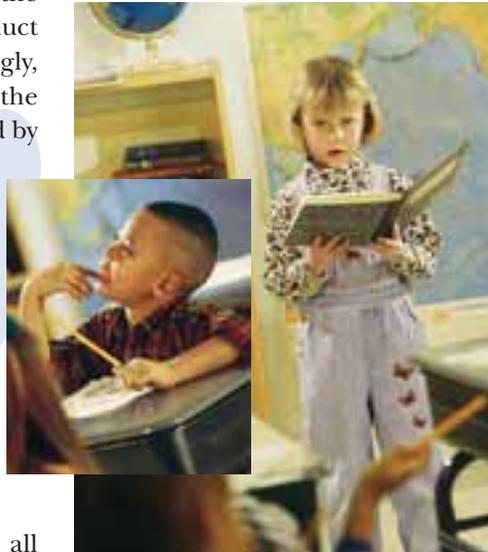
2 Common tests include WISC (Wechsler Intelligence Scale for Children) III or IV.

also determined using standardized tests. The child's symptoms are then described using standardized and scored questionnaires<sup>3</sup> based on the DSM-IV criteria set out above.

In addition, the child needs to be screened for co-morbid<sup>4</sup> conditions such as anxiety or depression, by a pediatrician who will evaluate the child's medical history and conduct a physical examination. Accordingly, a physician can also rule out the presence of microcephaly<sup>5</sup> caused by a fetal infection, fetal alcohol syndrome or fetal alcohol effects, neurofibromatosis<sup>6</sup>, hyperthyroidism, or petit mal seizures<sup>7</sup>, for example. If these conditions or diseases are present then the symptoms of inattention and impulsivity would be attributed to the underlying condition and not to ADHD. Once all of this information is gathered, and if all the criteria for ADHD are fulfilled, a diagnosis can be made with reasonable certainty. It is at this time that I recommend that you begin to explore treatment options for your child.

A major point that I would like to stress from the outset is that in the ideal, ADHD should be treated multimodally and not with medication alone. It is important that both you and your child understand that a diagnosis of ADHD is not a reflection of bad parenting or intentionally bad behavior on your son or daughter's part. In order to deal with some of the symptoms that your child may manifest at home,

you may benefit from joining a local or online parent support group where you can exchange valuable coping strategies with parents in similar situations. Sometimes, individual behavioral or family therapy may also be helpful in confronting the stress around your child's diagnosis and its manifestation.



In order to assure the best possible academic outcome for your child, cooperation and communication with your child's classroom teacher is essential. The teacher should be aware of strategies that can be used to assist you child in challenging times and additional tutoring in subjects where your child may be experiencing difficulty can enhance the whole treatment plan.

Lastly, and equally important, stimulant medications have been proven to be both effective and safe in controlling the symptoms of ADHD. The medications do not 'cure' ADHD but they do ameliorate the

symptoms thereby enabling the other aforementioned strategies to be applied more successfully. Stimulant medications, however, should always be considered a therapeutic trial and if there is no response to an adequate dose, this may be a clue that the diagnosis is inaccurate and that other psychiatric or medical diagnoses need to be considered.

The Canadian Attention-Deficit/Hyperactivity Disorder Resource Alliance (CADDRA) provides many resources for parents of children with ADHD on its web site [www.caddra.ca](http://www.caddra.ca). Additional resources may be found on the Canadian Pediatric Society website ([www.cps.ca](http://www.cps.ca)) and the American Academy of Pediatrics website ([www.aap.org](http://www.aap.org)).

Finally, if your child has been diagnosed with ADHD, don't panic but make use of the many advances in the diagnosis and treatment of this condition to enable your child to achieve his or her potential.

Stay tuned for the Fall edition of *Exceptional Family*, when I will review common stimulant medications prescribed for the treatment of ADHD and answer the questions raised in my introduction!

**Dr. Richard Haber** is an Associate Professor of Pediatrics at McGill University and the Director of the Pediatric Consultation Center at the Montreal Children's Hospital. He is also a Community Pediatrician.

<sup>3</sup> Examples of such questionnaires include Conners, SNAP IV and Stoneybrooke, among others.

<sup>4</sup> Co-morbid means two conditions are both present but not causally linked; i.e. ADHD does not cause anxiety or depression or oppositional behavioral disorder.

<sup>5</sup> Microcephaly is a head size which is two standard deviations below the standard curve of head circumferences = a small head.

<sup>6</sup> Neurofibromatosis is a genetic disorder which is associated with a variety of tumors (neurofibromas) in the brain and nervous system causing a variety of symptoms.

<sup>7</sup> Petit mal seizures are a type of seizure characterized by a specific electroencephalographic pattern and a particular clinical pattern in which the child has very brief absence spells.



## The “special needs” of exceptional siblings

Siblings of exceptional children experience many complex emotions. While some may resent and express jealousy over the extra attention paid to their exceptional brothers and sisters, others may express anger or guilt around their diagnosis. Additionally, some may worry that they may “catch” the disability or that they are carrying the same genes as their affected sibling.

Some children may also feel embarrassed by their siblings’ inappropriate behaviors and annoyed or agitated by them. Feeling anxious, isolated and confused are quite common reactions to the uncertainty that surrounds the diagnosis of an exceptional sibling. Finally, many children communicate their conflicting emotions by acting out, conveying a perfect image or covering up success.

Many mothers and fathers may initially become so overwhelmed by their own emotions and responsibilities around their exceptional child that they may inadvertently neglect the siblings’ needs.

On the flip side, siblings can be wonderful role models, playmates and teachers to the exceptional family member. Siblings often have unique bonds with their exceptional brother or sister and strive to protect them from life’s harsh experiences.

---

*Siblings of exceptional children often grow up to become caring, sensitive and giving adults who embrace diversity and are more accepting of others with differences.*

---

Moreover, siblings of exceptional children often grow up to become caring, sensitive and giving adults who embrace diversity and are more accepting of others with differences. Many pursue careers in the “helping” professions and contribute to society in special ways, for example, researching disabilities or fundraising and advocating for exceptional people, with a true passion that few others possess.

The following suggestions may help to ensure that your child’s experience in relation to his or her exceptional sibling will be largely positive:

- Find a balance between enlisting the help and support of siblings, while allowing them to have childhood fun and be themselves.
- Establish regular family meetings or brainstorming sessions where all members of the family have a chance to vent and share their feelings. Have each member of the family say nice things about the others, so that they will be able to appreciate the positives. Incorporate role-playing to help siblings understand the varying perspectives of other individuals.
- Listen to their emotions and do not criticize them. All feelings, including ones of embarrassment, resentment and jealousy, should be validated. Offer the siblings help in trying to work through them. Remember that each of your children is unique and consequently each will process their exceptional sibling’s condition differently, at his or her own pace. Each family member’s perception is their own truth.
- Recognize that all siblings naturally compete with each other and have conflicts even when there are no exceptional children in the family. Understanding this may help put things into perspective for parents who may otherwise mistakenly interpret their children’s “normal” conflicts as a sign



that they are acting out around the exceptional family member.

- If sibling rivalry escalates, act as a coach, not a referee. Encourage successes and foster team-playing between siblings. Don't take sides.
- Parents often use behavioral management techniques such as charts and prizes for their exceptional child. Remember to do this for the child's siblings as well, so that familial behaviors, expectations and consequences are clearly defined for all children. While target behaviors may be different for the siblings, the tools should be the same (i.e. chart or contract) so that all of the children feel on par.
- Don't let siblings fall into roles like the "good one" or the "patient one"; this only exerts additional pressure on the children to be perfect.
- Define the concept of "fairness" to the siblings by explaining that each child in the family gets what he or she requires, which means that sometimes the exceptional child may require more attention in a given situation. (This may be a very hard concept, especially for younger children to understand). The important thing to stress is that your love is equal for all of them.

- Find a family support group. Most people find comfort in talking to others who are in the same situation. Only other siblings of exceptional children can understand what they are going through. The "being in the same boat experience" can be very helpful. There is also a tremendous amount of literature geared to children of all ages that covers the subject of being the sibling of an exceptional child.
- Teaching the siblings relaxation techniques may help them to manage their anxiety, anger or frustrations.
- Sometimes, the attention accorded to "mainstream" siblings is often compromised by



the needs of an exceptional child. Alone time with one or both parents is very important as it conveys to the child that he or she is special and valued as much as the exceptional family member. Allowing siblings to spend respite-time at relatives or friends' houses can be very therapeutic as well.

- Explain to siblings about the disabilities of their brother or sister. (While some parents may fear that the siblings may use the information against the exceptional child, most inherently know that it is inappropriate to use as ammunition for teasing.)
- Answer siblings' questions honestly, without overwhelming them with too much detail. Expect that they will return with further questions when they are ready to process more complex information.<sup>1</sup>
- Finally and perhaps most importantly, remember that we all have "special needs." Each child needs love, respect, and attention. Each needs to be allowed to be him or herself and to be respected and supported for his or her distinct personality traits, strengths and weaknesses.

<sup>1</sup> Ideas on information sharing adapted from "Ask the Expert" by Veeta Engel (Spring 2006)

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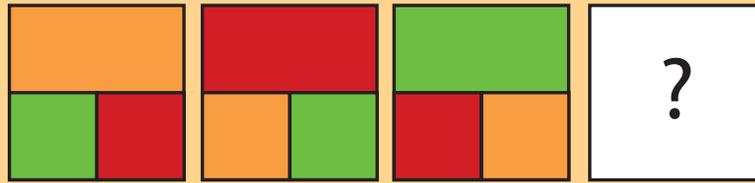
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**Dr. Harriet Greenstone** is a Psychologist and the Director of Centre MDC, a multidisciplinary care centre, specializing in children, adolescents, and adult evaluations and treatments. Harriet has done extensive work in developmental and learning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



# *Enhancing the intelligence of our children*

*Insights from Rafi Feuerstein, Vice Chairman of the  
International Center for the Enhancement of Learning Potential*

by AVIVA ENGEL

Like many parents of exceptional children, Rafi Feuerstein was inspired to work in a special needs field when his son was born with Down syndrome 17 years ago. An ordained Rabbi and Religious Judge from Jerusalem, Feuerstein originally had his heart set on a different profession. “When my son was born, I realized how apathetic I am as a human being. I never thought that I was so apathetic, but from time to time, life’s tests act as a mirror to show you who you are. I had plans and dreams and to be a therapist was not one of them. But I decided to change my ideas and become the psychologist of my own child.”

Fortunately for Feuerstein, he did not have to search beyond his own family to find a mentor to guide him in his ultimate career path. You see, Rafi is the son of Professor Reuven Feuerstein, internationally renowned for his theories of Structural Cognitive Modifiability (SCM) and the Mediated Learning

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*The only stable thing in  
humans is the fact that  
they are not stable.*

*You won’t find many  
people who won’t agree  
that we are constantly  
growing and changing.*

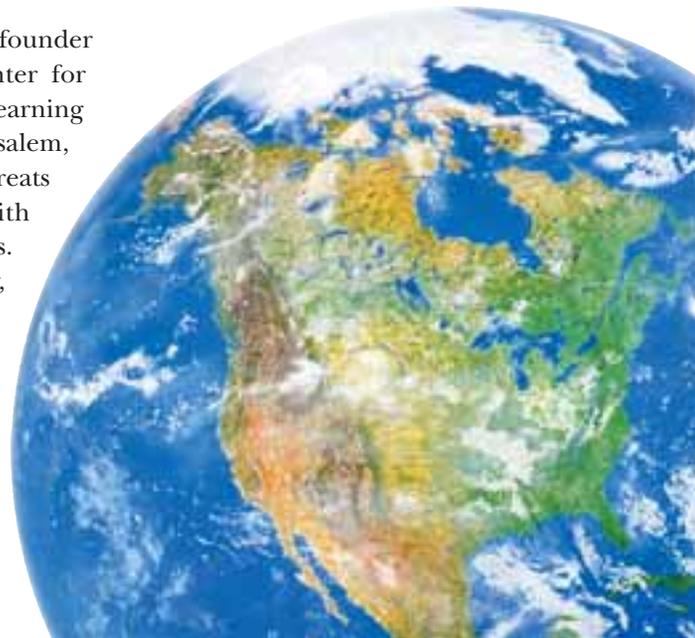
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Experience (MLE)<sup>1</sup> and founder of the International Center for the Enhancement of Learning Potential (ICELP) in Jerusalem, a center that primarily treats exceptional children with varying needs and abilities. A student of André Rey, Jean Piaget and Carl Jung who completed his doctorate in developmental psychology at the Sorbonne, Professor Feuerstein’s works

have been translated into eighteen languages including Braille and been taught in over 50 countries.

Today, Rafi works alongside his octogenarian father as the Vice-Chairman of the ICELP. Since the mid-seventies the centre has taught over twenty-five thousand instructors from around the world. The ICELP currently has a waiting list of over 2000 children and oversees more than 70 authorized training centres in 33 countries.

<sup>1</sup> SCM and MLE represent only a couple of Reuven Feuerstein’s many theories.



At a recent lecture in Montreal sponsored by the Montreal Feuerstein Student Initiative, Rafi Feuerstein briefly outlined the principles behind his father's theories of Structural Cognitive Modifiability and the Mediated Learning Experience. The following is an abbreviated transcript of his address:

### **Structural Cognitive Modifiability: An overview**

*If you come away with one message this evening, it is that the only stable thing in humans is the fact that they are not stable. You won't find many people who won't agree that we are constantly growing and changing. Everyone can remember himself 10 or 20 years ago. You're not the same now as you were then. The key concept behind my father's work is the postulate that each human is modifiable; that to be a human being means to have the ability to change in a random way - not just your knowledge, not just your behavior, but your abilities, your thinking skills and your learning skills.*

*The idea of modifiability interested my father very much. He once had an argument with his mentor of five years, the renowned cognitive-developmental psychologist Jean Piaget. He was his student in Geneva in the late 50's, early 60's. His question [to Piaget] was the following: "When*

*you talk about child-development step by step, stage after stage and you don't accept the idea of modifiability,*



Rabbi Rafi Feuerstein

---

*Intelligence is not seen  
as a fixed attribute  
but rather as the  
ability to learn.*

---

*how do you explain the fact that human beings are so different? Go to different continents. The differences are not just in the content of their values, knowledge and habits. The differences are also in the type of thinking, the way people understand time, organize space and the way they come to conclusions. How do you*

*explain it? How do you explain that we are so different?"*

*Professor Feuerstein asserted that the variety and the diversity that exist in human civilization are outcomes of modifiability. His main argument was against one of the strong symbols of our culture, which is the I.Q. test - not just as a specific technique, but as a philosophical symbol that paints the human being as an entity where genes are the main factor responsible for a person's level of functioning. While he accepts the existence of heredity, chromosomes he believes, do not have the last word. Intelligence then, is not seen as a fixed attribute but rather as the ability to learn.*

*Thanks to the genome project, in the future, when a child wants to go to university, he will simply take a blood test, the results of which will be determined in a laboratory and the answer [of whether he has been accepted to the university] will come in the mail; 'We checked your chromosomes, we know that you are dyslexic.' With behavioral genetics, once we can identify the specific chromosomes responsible for certain conditions, the decisions will be based on blood tests. Where is humanity? Where is freedom? There is none.*

*This is a philosophy that depicts a human being as an object, as something similar to a computer with a program in it. When a teacher or parent uses the term "the child IS" it doesn't matter what a child "is" - he can be brilliant or challenging - you are speaking in the language of "traits". When my son was younger, his teacher once told me that he read better than all of the other eight kids in his mainstream class. But then the teacher qualified her statement by explaining that the reason my son excelled at reading was because the other students were all dyslexic. The*

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Professor Reuven Feuerstein assesses a child at the ICELP International Workshops in Paris in 2005.

*literature on Down syndrome defines my son as having mild to moderate retardation. But as for his ability to read and write? That was easy, according to his teacher. [In her mind] he only has Down syndrome – It's not a serious thing! On the other hand, dyslexia [in her mind,] is a virus. 'Don't touch any dyslexic person', was her belief. 'Would you tell someone without legs to run? How can you tell a dyslexic person to read?' That's man-made dyslexia. We call it a trait. It's dangerous.*

*The teacher is not guilty. She's an amazing teacher. She just had one problem: She didn't transfer her knowledge from one area to another. It didn't occur to her that if she could treat a child with Down syndrome who has a chromosomal problem, she could treat a child with dyslexia, even though its source is still unknown.*

2 Dyscalculia is a learning difficulty affecting a person's ability to understand and/or manipulate numbers. Like dyslexia, dyscalculia can be caused by a visual perceptual deficit. Dyscalculia is often used to refer specifically to the inability to perform operations in math or arithmetic, but is defined by some educational professionals as a more fundamental inability to conceptualize numbers themselves as an abstract concept of comparative quantities.

3 Dysgraphia is a learning difficulty which impacts on a learner's ability to present the written word. People with this disorder have difficulty with handwriting. Their writing is usually not legible and not written at an age-appropriate speed. Problems might be seen in the motor patterns used during writing, as well as difficulties with spelling and written composition.

*I told my son's teacher, 'If you would invest 10 per cent of what you invested in my son, then there would be no dyslexia, no dyscalculia<sup>2</sup>, no dysgraphia<sup>3</sup>.' When you define a child as "learning-disabled" once, he will be learning-disabled forever.*

*When you define  
a child as  
"learning-disabled"  
once, he will be learn-  
ing-disabled forever.*

*Using the language of "traits" denies modifiability. Instead, it is preferable to use the language of "states" and say, "Her behavior is..." In doing so, you are acknowledging that the child's behavior is contingent on many factors and not simply something that is based solely on an internal whim. This is a dynamic way of describing human beings.*

## Mediated Learning Experience: An overview

*Professor Feuerstein believes that education plays a crucial role in the growth and cognitive development of an individual. Learning is achieved via two modalities: One modality is what we call a direct modality of learning - I see you, I see books, I see a room. But direct learning is dependent on indirect or mediated learning, which is the second modality. As parents and educators, each of us can serve as a mediator between the world and our children.*

*The child sees things directly. However for him to benefit from direct learning, he needs to be mediated by someone who uses environmental stimuli to equip the child with the prerequisites to think independently in the future. The ability to modify comes from mediation. Because when a child is mediated, he gains the ability to learn, to understand, to grow.*

*A parent who feeds his child dinner while simultaneously reading the newspaper, answering the phone, or*



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*When mediating with your child, Feuerstein suggests the following:*

- Think of your child as though she just landed on the moon. It's her first day in our world. She knows nothing; everything is new to her.
- Remember that it is the quality, not the quantity of the interaction that matters.
- Compare things. Ask your child questions, around the sizes, textures, colors and weights of objects, for example.
- Transform simple, daily situations into meaningful lessons. Use time that is often wasted, like mealtime, dressing time or time in the car, to mediate.

*checking his e-mail is not a mediator. To be a mediator is to describe the food that you're giving to your child - to use transcendence, to go beyond the concrete stimuli, which is the food, and add a concept, like the concept of "hot", for example. The difference between a concept and a word lies in establishing a frame of reference for the child. So, not only would you*

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*I want to send parents a message: I want to convince them that there is hope, that there is the ability to modify your children.*

---

*merely say, "The soup is hot", you might say, "The soup is hot like the sun". A mediator teaches the child that there's a language of concepts, a language of symbols and comparisons that represent concrete reality. Similarly, a parent who punishes her child without explaining the reason behind it is not a mediator. The child will only learn that the world is irrational and he will behave irrationally in the future. But a child who is mediated is taught the reasons and explanations for things. Such a child learns to understand that the*



*Professor Reuven Feuerstein assesses a young adult at the ICELP International Workshops in Paris in 2005.*

*social world is built on cause and effect. This is mediation.*

*My father views children who are born with what we call learning disabilities, retardation, ADHD, Down syndrome, autism etcetera as children who were born in the world covered by a curtain. The essence of all of our clinical work is to save these children by identifying a hole in this curtain. We try to see how we could use the hole, even if it's small, to bring information into their inner world. I want to send parents a message: I want to convince them that there is hope, that there is the ability to modify your children. You may struggle to find the hole in the curtain. But fight. Never accept the fate of a title, of a diagnosis.*

*To learn more about the Feuerstein Methodologies, visit [www.icelp.org](http://www.icelp.org)*

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# Adapted Travel

A column dedicated to traveling with *exceptional children*

## An exceptional Big Apple experience

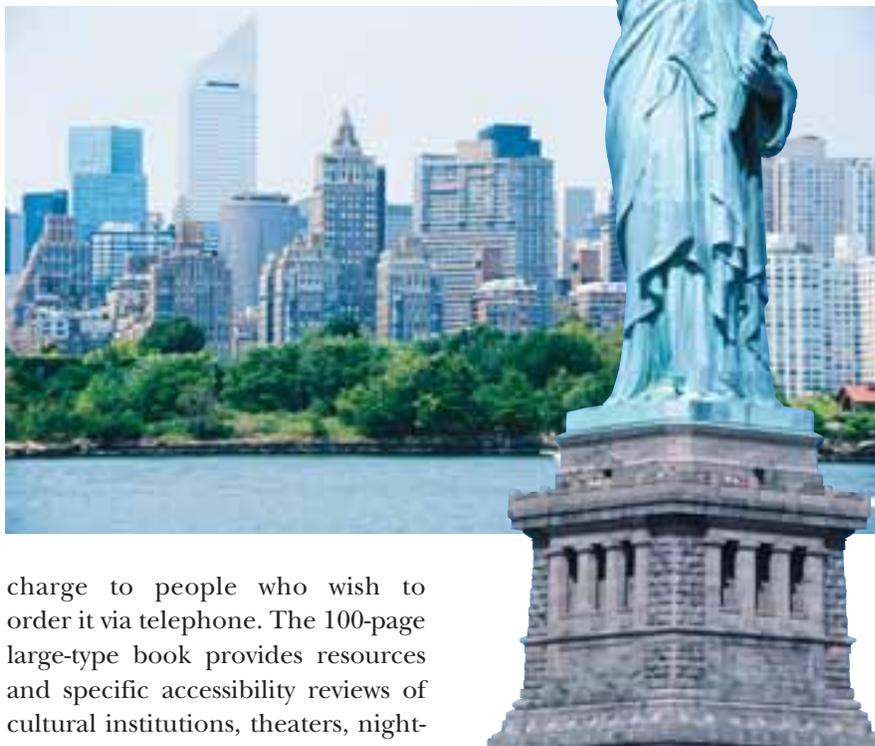
by MIKE COHEN



Five years after the infamous 9/11 terrorist attacks tragically took thousands of innocent lives, destroyed the Twin Towers and shocked

the world, one of the planet's most exhilarating destinations is buzzing with electricity. New York City has certainly cranked up the volume in 2006, with a dizzying<sup>1</sup> array of new hotels, global cuisine, breathtaking attractions, blockbuster Broadway shows, fabulous exhibitions and, of course, incomparable shopping.

Before you start planning your trip, I encourage you to log on to the NYC & Company website ([www.nycvisit.com](http://www.nycvisit.com)). All of New York's public buses are wheelchair accessible and individual door-to-door Para-transit service is available for people with limited mobility who may be unable to use public bus or subway service. While not every subway station is wheelchair-accessible, many stations contain elevators, ramps, visual display signs, accessible public telephones, and audio features on vending machines. The Mayor's Office for People with Disabilities (212-788-2830) will mail the book *Access New York* free of



charge to people who wish to order it via telephone. The 100-page large-type book provides resources and specific accessibility reviews of cultural institutions, theaters, nightlife, sports venues, and tours.

Visitors looking for a personalized orientation to NYC need only call Big Apple Greeter (212/669-8159, 212/669-3602, TTY 212/669-8273). With more than 10 years of experience, the organization has connected more than 30,000 visitors with its 500 volunteer residents (Greeters) for free visits to New York City neighborhoods.

### Hotel accommodations

Located in one of the city's most exciting and central neighborhoods at 371 Seventh Avenue and 31st

Street, the Affinia Manhattan ([www.affinia.com](http://www.affinia.com)) is truly an upscale suite hotel at the center of it all – if you can swing it financially and want to treat the family to a luxury getaway. Close to transportation, entertainment, Macy's, Madison Square Garden and other world-famous attractions, guests can take advantage of all the city has to offer with remarkable ease. The Affinia's lobby is a hub of activity, complete with a Metro Concierge - the hotel's "city specialist" - who stands at a unique multimedia post offering New York expertise and an insider's perspective. Amenities such as city-focused

<sup>1</sup> Recognizing that New York City is quite literally a "dizzying" place, I do not recommend this travel destination for anyone who has trouble with sensory integration. The city is extremely congested with people, cars, odors and noise – all of which would be extremely overwhelming for a child with sensory integration dysfunction.



Some of New York City's more memorable Broadway shows

activity kits and a library of NYC-themed books help guests plan their New York experience from the moment they arrive. If requested, the hotel will happily provide guests with a DVD player, which will undoubtedly be put to good use by those traveling with children.

Affinia Manhattan suites provide plenty of room to spread out and relax with ample space for entertaining. Deluxe suites on the hotel's top floors offer spectacular views and exclusive amenities such as plush robes and evening turndown service. For the ultimate night's sleep, guests can make a selection

from the Affinia Pillow Menu, featuring a choice of three signature pillows. The hotel's complimentary parking service comes in handy for anyone choosing not to brave NYC's notorious traffic-jammed streets.

For people with hearing impairments, the Affinia has rooms with doorbells that light up when rung. The hotel also offers Teletype phones and ambulatory rooms



for guests who use wheelchairs, complete with roll-in showers. The Guest Services manager will strive to accommodate any exceptional guests who have additional needs. For more information call 1-866-AFFINIA.

Families seeking more modest, less pricey accommodations may wish to consider staying in nearby New Jersey and making the short commute to NYC. For more information

on lodging in New Jersey, visit [www.newjerseyvisitorsnetwork.com](http://www.newjerseyvisitorsnetwork.com).

## Broadway experience

Getting tickets to certain Broadway shows is not easy. Although I began searching online several months in advance of my trip for tickets to various productions, I discovered that the shows my family was most interested in were virtually sold-out. Ultimately, we settled on *Wicked* and *Hairspray*. The prices were extremely high, but I held my nose and ordered them online anyway. The shows were good, but the best bargain for my money was the League of American Theatres and Producers' official Broadway Open House ([www.broadway.org](http://www.broadway.org)),

a two-hour "insider's" walking-tour through Manhattan's Theater District that explores the interiors of Broadway theaters, offers fans an opportunity to hear legendary backstage stories and discover a rarely seen side of Broadway. Tours depart from the Broadway Ticket Center in the Times



Square Information Center on the East side of Broadway between 46<sup>th</sup> and 47<sup>th</sup> five days per week (Tuesday through Saturday) at 10:00 am; from September 1 through December 31, three days per week (Wednesday, Friday and Saturday) and from Jan. 1 to March 31, twice weekly (Wednesday and Saturday). While I recommend this tour for children ages six and over, children should have the stamina to endure the two-hour tour and all of the walking that it entails. Most importantly, comfortable shoes are a must!!

For patrons who use wheelchairs, arrangements can be made for a



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tour operator to push them. People who use walkers or crutches may be accompanied by separate tour guides so that they can participate at their own pace without feeling pressured to keep up with the group. All of the theatres visited on the tour are equipped with outdoor ramps and no stairs are involved once inside.

Many theatrical productions and musical performances offer discounts for people with physical disabilities. Tickets are available through individual theater box offices or through the Tele-Charge Access Services hotline at (212) 239-6222. For people with hearing impairments, the Hands On! Organization arranges sign language interpretation for many cultural events in NYC, including museum exhibitions, theater productions, and film screenings. Theatre Development Fund's Theatre Access Project offers open-caption<sup>2</sup> and sign-interpreted performances for many Broadway and Off-Broadway productions, and also arranges access for people who use wheelchairs. Hospital Audiences, Inc. provides an audio-description service for theatergoers with visual impairments who wish to take in the action on stage.

## Where to go

New York's famous Empire State Building ([www.esbnyc.com](http://www.esbnyc.com)), a New York City Landmark and a National Historic Landmark, soars more than a quarter of a mile into the atmosphere above the heart of Manhattan. Located on the 86th floor, 1,050 feet (320 meters) above the city's bustling streets, the Observatory offers panoramic views from within a glass-enclosed pavilion and from the surrounding open-air promenade. Since the Observatory



*Empire State Building*

opened to the public in 1931, the awe-inspiring sight of the city beneath them has wowed almost 110 million visitors. The building is entirely wheelchair-accessible, and includes accessible bathrooms on the Concourse level and 86th floor observation deck. The deck itself has accessible viewing-windows and binoculars. All elevators have lower-reaching selection panels, which are also in Braille.

Admission to the Empire State Building is US\$16.00. Lineups to enter the Empire State Building can be extremely long. However, those who have difficulty waiting in line for extensive periods of time may use an express line at a cost of US\$40.00.



*Red Panda*

If animals interest you, the Central Park Zoo ([www.centralparkzoo.com](http://www.centralparkzoo.com)) is well situated, wheelchair-accessible and full of life. From a steamy rain forest to an icy Antarctic penguin habitat, the zoo leads visitors through Tropic, temperate and Polar regions in which they encounter fascinating animals - from tiny leafcutter ants to tremendous polar bears. The Tisch Children's Zoo, added in 1997, lets little animal lovers explore gentle creatures up close. Year-round education classes and innovative public programs - including the zoo's "Wildlife Theater" - encourage all ages to learn more about our natural

world and become involved in its protection. Through the American Zoo and Aquarium Association's (AZA) Species Survival Program, the zoo is actively involved in helping endangered species, including rare tamarin monkeys, Wyoming toads, thick-billed parrots, and red pandas. Guests with visual impairments or autism who use service animals may bring them into the zoo, provided that the animals remain properly leashed. Guests are solely responsible for the care and control of their animals.

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<sup>2</sup> With open captioning, dialogue is projected on a screen in plain-view of the audience.

New York is a city of museums, many of which are wheelchair accessible. But if you can visit only one, I recommend The American Museum of Natural History ([www.amnh.org](http://www.amnh.org)) located at Central Park West and 79<sup>th</sup> Street. Established in 1869, the museum has played a leading role in exploration, discovery, and theoretical advances in the natural sciences. Divided into five sections including Anthropology, Paleontology, Invertebrate Zoology, Vertebrate Zoology, and Physical Sciences, the museum is well-organized and easily navigated. The museum also boasts the Rose Center for Earth and Space, the V. Starr Natural Science Building, an IMAX Theatre (not recommended for people with sensory-integration dysfunction due to the films' in-your-face visuals and overwhelming sound-effects), an amazing Butterfly Conservatory and the Cosmic Collisions planetarium - all of which are must-stops.

The Rose Center and parking garage entrances are wheelchair accessible, as is the 77<sup>th</sup> Street entrance for programs only. All video displays are captioned for people with hearing impairments and headsets and neck loops<sup>3</sup> are available upon request in theaters. Closed-captioning is available for certain IMAX movies while scripts and synopses are available for shows at the planetarium.

Also worth a visit is Madame Tussauds New York on 42<sup>nd</sup> Street, where you can get up close and personal with some of the world's most interesting personalities. I rubbed elbows with the likes of Woody Allen, Golda Meir, Bill Clinton, Nelson Mandela, Lindsay Lohan, Jessica Simpson, Whoopi Goldberg



*Rose Center for Earth and Space*



*Toys R Us Times Square*

and many more. You can even visit the wax double of American Idol judge Simon Cowell and attempt to wow him in a great karaoke setup. Madame Tussauds New York is wheelchair accessible and wheelchairs are available upon request at the box office on a first-come, first-served basis. While children eight years and over who are well-versed in pop culture may find this museum interesting, parents may find that it does not offer the kind of stimulation that would sustain their child's attention and interest. Madame Tussauds New York will also likely be unappealing to

children with autism who typically have difficulty relating to others' emotions and facial expressions.

## Toys, toys, everywhere

Last but not least, Toys R Us Times Square is a MUST SEE for toy-lovers of all ages. A virtual play-kingdom spanning four floors, Toys R Us Times Square features a giant indoor Ferris wheel where kids can ride on their favorite toy characters, a colossal Barbie Playhouse, gigantic Thomas the Tank Engine railroad set and a candy store called – you guessed it – Candyland, complete with life-size characters from the timeless board game and giant M&M's.

Toys R Us Times Square<sup>4</sup> is not recommended, however, for anyone with sensory integration dysfunction or ADHD; the hundreds of people who frequent the store at any given time combined with constant music, sound effects and an overwhelming amount of toys, can assault the senses of even the most tolerant "neurotypical" person. The store also features an enormous, five-ton, 20-foot-high T-Rex from Jurassic Park™ that belts out intermittent roars every few seconds. While older kids will surely be fascinated by the dino's realistic features, young children will find the T-Rex incredibly scary, as will children with autism who may not be able to differentiate between real and pretend.

**Mike Cohen** is a Montreal writer, the Communications and Marketing specialist for the English Montreal School Board and a Côte Saint-Luc city councilor. Contact Mike at [info@mikecohen.ca](mailto:info@mikecohen.ca).

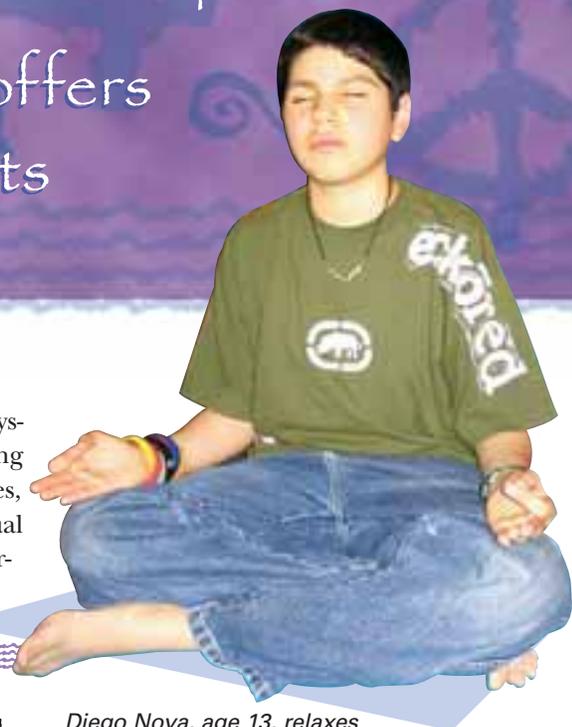
<sup>3</sup> A neck loop is a hearing-enabling device that loops around one's neck.

<sup>4</sup> It must be noted again, that Times Square in particular (and even more so at night) is especially populated and boisterous and is therefore not recommended for anyone easily affected by sensory overload. The sheer brightness of the neon signs alone is enough to make anyone overwhelmed.

# Yoga-based therapy

for exceptional children and adolescents with special needs

Holistic exercise offers multiple benefits



by THOMAS HENDERSON

Yoga. Everyone is doing it! From yoga courses and studios to mats and apparel, DVD's and books, yoga has become all the rage as more and more people are discovering the activity's physical and emotional benefits. And now, centers across North America are increasingly offering yoga programs that cater to exceptional children and adolescents with Autism Spectrum Disorder (ASD), ADD/ADHD, Down syndrome, learning disabilities, dyspraxia, cerebral palsy, and a variety of other special needs.

The word "yoga" comes from the Sanskrit word *Yug*, which means *union* or *joining*. Yoga consists of a wide variety of activities, including person-centered exercises that incorporate breathing and meditation techniques, aimed at improving all aspects of being: emotional, psychological, physical, and social.

Yoga provides an effective set of exercises to benefit the whole body. Muscle tone and

flexibility are honed through systematic stretching and maintaining of postures. Movement sequences, called *vinyasa*, are taught, with visual support, to improve praxis (motor-planning), coordination and

With increased body awareness and fitness, comes self-confidence and openness to learning.

bi-lateral functioning of the body. Another important aspect of the program is body-awareness. Adapted-yoga participants are encouraged to experientially discover their body: its functions, sensation, and anatomy. Yoga poses also benefit alignment, balance, strength and support healthy posture. With increased body awareness and fitness, comes self-confidence and openness to learning.

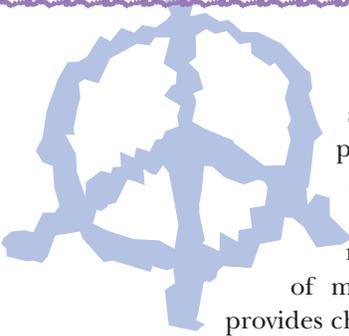
Moreover, its therapeutic quality and flexibility combined with the

*Diego Noya, age 13, relaxes his mind and body through meditation.*

fact that it is a non-judgmental and non-competitive pursuit make it an ideal approach to help address a gamut of issues, concerns and goals that any person might have.

For children and teens with special needs, an adapted yoga program may not only address a variety of their unique concerns, but also serve to promote self-confidence and social communication. Furthermore, adapted yoga provides an incredible opportunity for participants to build their self-esteem while interacting and enjoying an activity with peers. It also enables them to be proud of their achievements, gain a sense of mastery and to 'own' an interest.

For many parents, finding extracurricular activities that their excep-



tional child can successfully take-part in is challenging. The highly structured and repetitive nature of most yoga classes provides children and teens

with a predictable, secure environment and routines that encourage participation and are conducive to learning. This structure is supported by schedules, visual supports, and even the physical boundary of a yoga mat, which helps to define and organize participants' use of space.

Among other benefits, yoga instructors find that movement activities help to stimulate language acquisition and expression. The students also experiment with a lot of the non-verbal skills inherent in communication: posture, expression, proximity (the use of personal space) and gestures. In my own adapted-yoga program, I also attempt to stimulate participants' creative thinking by revolving each class around a different theme on which discussions and creative group projects, like drawing and acting, are based.

Perhaps most remarkable, is yoga's ability to minimize the specific challenges of exceptional children, including sensory integration dysfunction, self-regulation issues and anxiety-management problems.

## Sensory integration

Children and adolescents with ASD, as well as those with other developmental disabilities, often experience sensory integration dysfunction, which manifests in either a heightened or under-responsive reaction to sensory stimuli. Yoga postures and movement sequences provide a deep source of stable proprioceptive<sup>1</sup> input. By holding postures, the child's body starts to recognize and make adjustments based on sensory signals. Accordingly, the muscles, joints, and tendons 'teach' awareness of body position. The central



Robin Mahar (L) and Owen Nickols (R), both 10, practice deep breathing with yoga instructor Thomas Henderson.

nervous system is also affected, allowing the participant to process and modulate sensory information in a more organized and appropriate way. Another important aspect of yoga class is balance. The vestibular systems<sup>2</sup> of many exceptional people are also often hypo or hyper-reactive,

resulting in either apprehensive and fearful responses to movement or, on the other end of the spectrum, a search for intense sensory experiences. Controlled balancing activities and postures involving inversion (upside-down positions) have shown to be very therapeutically effective in this regard.

## Self-awareness, emotional regulation and anxiety management

Self-awareness and emotional regulation are supported and taught by using a cognitive behavioral approach in yoga class. Students learn to self-regulate using metacognitive<sup>3</sup>, behavioral (physical), and language strategies. Since children and adolescents with sensory processing difficulties often experience highly fluctuating arousal levels, a combination of physical exercises that provide sensory stimulation and relaxation techniques can really help to stabilize these fluctuations.

Breathing is a very important aspect of any yoga class and directly affects anxiety management. Participants

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1 Proprioception is the unconscious perception of movement and spatial orientation arising from stimuli within the body itself (muscles, joints, tendons, ligaments and connective tissue).  
2 The vestibular system is the system in the body (inner ear) responsible for maintaining the body's orientation in space, balance, and posture. It also regulates locomotion and other movements and keeps objects in visual focus as the body moves.  
3 Metacognitive refers to a person's knowledge of the functioning of his or her own mind and his or her conscious efforts to monitor or control this functioning.

are instructed in a variety of deep breathing techniques, key to self-regulation. They also learn how to identify even low-level feelings of anxiety or agitation and employ meditation, visualization, systematic



Students practice various poses such as "Downward Facing Dog", at Giant Steps' after-school yoga program.

relaxation of specific body parts, self-massage and still-resting (called *shavasana*: lying supine on the floor with eyes closed) to self-regulate their levels of arousal and anxiety.

As ASD and other developmental disabilities become increasingly diagnosed, there is a growing need for therapeutic interventions that target the whole exceptional child and allow him or her to participate as an *equal*, rather than merely as a 'client' or 'patient'. By definition, yoga is an excellent example of such a program. Because of its potential to address a person's multiple facets (physical/emotional/

social), participants' parents report a high-degree of generalization of their children's skills across different environments, both academic and social. Yoga is multi-disciplinary and encourages overall personal development. Students experientially learn and grow alongside peers in a safe, fun, and non-competitive environment that provides a true sense of belonging and success.

**Thomas Henderson** is a Social Skills Specialist and Training Coordinator at Giant Steps in Montreal and has developed and implemented an after-school Yoga program for children and teens with ASD. He also co-coordinates a summer theatre camp for exceptional children.

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## Boy with profound hearing loss sings for the Pope

A nine-year-old boy from Quebec who has a hereditary condition that causes deafness recently performed at the Vatican for Pope Benedict XVI and five Quebec Catholic cardinals prior to a blessing ceremony for the Ark of the New Covenant. Accompanied by his parents, Jérémy Gabriel sang the psalm "Je louera l'Éternel" before the Pope blessed the Quebec-built chest, which is decorated with images related to the Eucharist.



Born with Treacher Collins syndrome, a condition that is also characterized by underdeveloped cheek-bones, downward-slanting eyes, malformed ears and a small lower jaw, Gabriel has undergone 15 major corrective surgeries and has partial hearing thanks to an implant in his skull that captures sound waves. Having previously performed onstage with Celine Dion in Las Vegas and sung O Canada before 20,000 spectators at a Canadiens game in Montreal – a performance that drew him a standing ovation - Gabriel is no stranger to fame. He has also appeared on a number of French-language radio and TV shows and recently released a second CD. The child expressed a wish to sing for the Pope last year after watching media coverage of Pope John Paul II's funeral.



## ABC pilot includes character who has autism

The ABC Television Network will soon premier a new drama that touches upon a mother's challenges around raising her child who has autism. Touchstone TV's *Brothers & Sisters* is set in L.A. and centers around adult siblings and their grieving mother who come together after the sudden death of their father, the family patriarch. The cast includes Calista Flockhart of *Ally McBeal* fame, who narrates the story as the show's "most outspoken" sibling. *Brothers & Sisters* will air Sundays at 10:00 p.m. (ET).

## Tonsillectomies may cure ADHD

Researchers at the University of Michigan Sleep Disorders Center have found that children with Attention Deficit Hyperactivity Disorder (ADHD) who had tonsillectomies behaved better a year after their surgery. This latest research backs a theory that ADHD - a condition which affects approximately one in 12 children - is strongly linked to sleep-disorders. Researchers have drawn a correlation between sleep disturbances, like sleep apnea<sup>1</sup> and snoring and hyperactivity in children. Approximately half of children who have tonsillectomies have them because their enlarged tonsils and adenoids are hindering their ability to breathe. The study found that when the tonsils were removed, the children slept better and were calmer when awake.



The scientists compared 78 tonsillectomy patients between the ages of five and 13 with 27 children who had had other types of surgery. Prior to their operations, those who had had tonsillectomies had sleep and behavior problems more frequently than those in the control group. Of the 22 children who were diagnosed with ADHD prior to their tonsillectomies, 11 no longer had the diagnosis one year following the surgery. According to Dr. Ronald Chervin, director of the center and author of the study, tonsillectomies may benefit about a quarter of kids with ADHD – a substantial number given the condition's prevalence in children.

<sup>1</sup> Sleep apnea is characterized by temporary periods during sleep when one stops breathing.

## Magic Johnson to co-produce movie about teen with autism



A teenager who drew national attention in the U.S. after winning his basketball team's final home game of the season will be the subject of a new movie to be co-produced by basketball legend Magic Johnson. Seventeen-year-old Jason McElwain, aka J-Mac, of Rochester, New York, has autism and did not begin speaking until the age of five. In February, McElwain, who is the manager of the Greece Athena High School basketball team, made headlines after he entered his team's final home game with four minutes remaining. Despite the fact that it was his first and only game of the year, McElwain scored 20 points, won the game and was hoisted-up by his elated teammates. His victory sparked movie inquiries from approximately 25 Hollywood production companies, including The Walt Disney Co. and Warner Bros. Recently, Sony Corp.'s Columbia Pictures acquired the film rights. McElwain, who is at a Grade 4 level academically, lacks certain social skills but is said to get along well with his "mainstream" peers. AP NEWSWIRE

## In search of treatment a world away

The parents of a two-year-old boy with a rare metabolic disorder are moving their family of four from Ontario to England in the hopes of acquiring government-funded enzyme-replacement medication for their son that is not covered in Canada. Isaac McFayden has Maroteaux-Lamy syndrome, a degenerative condition that has caused an umbilical hernia, blurred vision and necessitated surgery to remove portions of his skull and vertebrae that were compressing his spinal cord.



The drug, called Naglazyme, is available in North America; however few patients can afford to pay the minimum annual cost of \$300,000 to obtain it. Because only three to 10 Canadians are affected by McFayden's disorder, the medication has not been reviewed by Health Canada and is therefore unlicensed. Under the Canadian government's special-access program, patients with life-threatening illnesses or disorders are permitted to acquire unlicensed medications in the absence of conventional treatments. The McFaydens' challenge lies in being able to fund Naglazyme for Isaac's lifetime use. Naglazyme is licensed throughout the European Union and funded by the government.

## Rats with spinal cord injuries regain partial ability to walk thanks to stem cells



Scientists at the Krembil Neuroscience Center at Toronto Western Research Institute have restored partial walking-ability in lab rats with spinal cord damage by injecting them with stem cells from the brains of mice. The rats, whose spines had been crushed, were simultaneously administered anti-rejection drugs. The cells merged with the injured spinal cord tissue and began to produce myelin, the insulating layer around nerve fibers that transmits signals to the brain. While the rats did not recover completely, they did regain a considerable ability to walk and support their weight and improved coordination in their joints. The findings have profound implications particularly for people who lack myelin and have paralysis consequent to spinal cord injury.

## Parents of boy with ADD "felt bullied" to put their son on Ritalin

The parents of a 12-year-old boy who was expelled indefinitely from school after his mother refused to give him Ritalin have launched a Quebec-wide suit on behalf of people who have felt coerced to put their children on the stimulant.



Despite having signed an intervention plan for her son Gabriel that included prescription medications to treat his hyperactivity and ADD, Danielle Lavigueur discontinued the drug in January because Gabriel was suffering from side effects including insomnia, aggressiveness and loss of appetite.

While officials at Lavigueur's school contend that his behavior became unmanageable around the same time that he ceased taking his prescription medications, they assert that the boy's expulsion was a result of his repeated failure to follow school rules around dress, hair color, behavior and academic performance. Lavigueur may return to school on condition that his parents comply with the intervention plan that they willingly signed – which includes the administration of Ritalin.



# Exceptional Family now available in audio format

*Thanks to an initiative of VoicePrint Canada, EF will now be available to people who are blind or have impaired vision.*

by LISA XING

Most Canadians typically start their day with a glance at newspaper headlines. It's something we take for granted. For the millions of Canadians who are blind, have low-vision or learning or physical disabilities that make it challenging for them to read, that simple pleasure is beyond their grasp. Fortunately, there's VoicePrint Canada, a unique media non-profit organization that broadcasts news, information and specialty programs 24-hours a day, seven days a week throughout the country.

With the help of volunteer readers, VoicePrint Canada broadcasts full-text articles from *Exceptional Family* and more than 600 other Canadian papers and magazines, reaching more than eight million Canadian households through local cable providers, satellite and the internet. In contrast to radio and television's characteristically brief news segments, VoicePrint allows readers to "hear" the entire story.



*Marianne d'Eon-Jones, an editor at VoicePrint Canada, explores EF with her daughter Diana, age 8.*

"To get in-depth coverage [of daily news] you have to read the newspaper," said fourth-year University of Toronto student Aman Singer, who started listening to VoicePrint in the 1990s, when there weren't many other forms of media accessible to people who are blind. "Its importance at that time can't be magnified. I found it was a lifeline," he said.

VoicePrint is the result of a movement that began in the 1980's when a pioneering group of people posed the following question to government: How could millions of vision and otherwise print-restricted Canadians get access to the published news and information they need to help them make the basic

decisions of every day life – and to help them fulfill their rights and responsibilities as citizens? In response, the Canadian Radio-television and Telecommunications Commission (CRTC) concluded



*George Cox, VoicePrint volunteer*

that VoicePrint's establishment "was not only in the public interest but a matter of national importance."

In March of 2001, VoicePrint Canada was officially named a mandatory service by the CRTC for larger broadcast distributors. "This means any cable or satellite company with more than 2,000 subscribers is required to carry the VoicePrint



(L to R) Charmaine Hucolak and Bud Kofman, VoicePrint Canada volunteers; Cathy D'Angelo giving orientation, and Bill Shackleton, the producer of VoicePrint Canada.

service,” said Arlene Patterson, Outreach Director of VoicePrint Canada. “That means more than 95 per cent of the country is covered.”

Today, VoicePrint is accessible through the secondary audio program (SAP) of CBC Newsworld, audio channels of ExpressVu, Star Choice and Look TV, Rogers Digital Channel 196 and via the Internet. Across Canada, close to 800 individuals from a variety of backgrounds volunteer to read selected articles. In Toronto, their 30-minute reports are recorded, edited and post-produced by studio technicians who are blind. The technicians also manage the network centre. VoicePrint has broadcast more news and information programming than all other Canadian television stations combined, with the exception of CBC Newsworld.

While VoicePrint was initially based in Toronto, regional offices were soon established in order to bring listeners up-to-date news and information on their respective regions. The regional broadcasts were such a hit that they sparked a demand for even more localized news and information. Listeners quickly expressed interest in hearing articles from their community publications so that they could be kept informed of news and events about their local City Halls, businesses and sports teams, for example. To meet their

needs, VoicePrint embarked on an ambitious new initiative in 2004 to increase and improve local service in such cities as Halifax, Edmonton, Calgary, Toronto, Sudbury and Vancouver. By the year 2010, VoicePrint hopes to have 100 broadcast centers in operation.

“The goal of our organization is to help break barriers that prevent people from accessing the media so they can independently access newspaper and magazine articles,” said Patterson. This is especially important in society today. By age 50, half the population will require prescription reading glasses. By 65, a large percentage of these people will be unable to see, to read the newspaper.<sup>1</sup>

“I think we’re each given a gift,” said Mike Morrison, a weekly volunteer reader from Toronto, who is grateful for his vision. “Those of us who have it have an obligation to share it.”

**VoicePrint** is proud to add *Exceptional Family* to the growing list of publications available in audio. *EF* airs on Saturdays and Sundays at 2:30 p.m. on the “*Ability Today*” program. It can also be found on VoicePrint’s Audio Archive. For more information on services and program schedules call 1-800-567-6755 ext 222 or visit [www.voiceprintcanada.com](http://www.voiceprintcanada.com). To access a local broadcast go to [www.voiceprintcanada.com](http://www.voiceprintcanada.com) and click on the Local Broadcast Center icon on the homepage.

<sup>1</sup> National Advisory Council on Aging, 1997

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## Helping an adolescent with sensory integration dysfunction manage his grooming routine

**Q** Our 17-year-old son Jay has moderate developmental delays and sensory integration dysfunction. While it has always been a struggle for us to care for his personal needs, lately it has become impossible to cut his hair, shave him or cut his nails due to his heightened sensitivity to touch and refusal to cooperate. He is physically large, which makes restraining him a non-viable option.

My husband feels that I put too much emphasis on Jay's appearance. He has no problem letting Jay go ungroomed for weeks at a time and rationalizes that most teens intentionally sport a rugged, unkempt look.

Besides the fact that Jay's uncouth, neglected appearance reflects negatively on us as his caregivers, I think we should do whatever we can to enhance Jay's appearance, so that others will treat him with the dignity and respect that he deserves. Is there some kind of middle-ground?

**A** The short answer to your question is yes, there is a middle ground. The challenge is in figuring out how to establish it. Your letter paints a picture of the struggle that it is to handle your son's grooming needs, but it also reflects the concomitant tension that you are experiencing as a mother, as a wife and as a member of society. If we are to address the question of finding



a middle ground, we will need to consider how doing so will play out in all of these areas, since they are all related to managing Jay's challenging behavior.

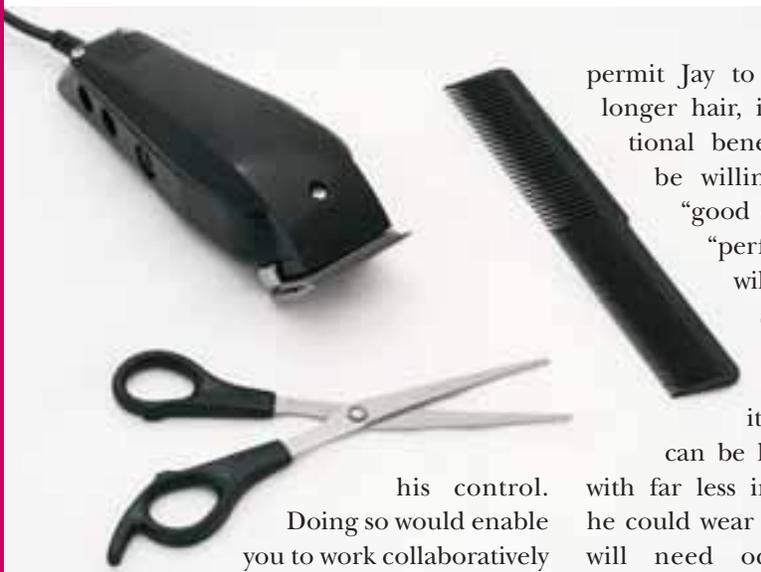
In my mind, finding a middle ground is associated with seeking balance and the need for compromise. Although I will offer some specific strategies to improve the grooming situation, having an attitude which embraces these concepts plays a major role. Since you are willing to find the middle ground, (as your letter conveys) you are already half way there.

Although you are no doubt familiar with the features of Jay's disabilities,

allow me to review them as a starting point so that the implications of his condition are clear. Developmental disabilities such as you describe in Jay's case, often go hand in hand with a dysfunctional sensory system, meaning that the brain is unable to properly process information brought in by the senses. Your letter makes reference to that part of Jay's sensory integration dysfunction which reflects particular sensitivity in the tactile system, leading to a negative emotional response to touch.

What this means is that Jay's distress at being groomed is genuine and that his lack of cooperation is the expression he gives to that distress. As well, the combination of Jay's sensory integration dysfunction and his adolescent development may help to explain why he has recently become even harder to manage. Many parents of children with developmental disabilities anecdotally report that as teenagers they show heightened aggressiveness.

Currently, it looks as though you and your husband are in a tug-of-war around how to manage Jay's grooming. This may be a displacement of your anger at Jay for rebuffing your caretaking efforts. Finding a middle ground means keeping Jay's response in perspective by reminding yourself that it is beyond



his control. Doing so would enable you to work collaboratively with your husband around how best to alleviate some of Jay's pain. It is worthwhile to consider how continuing to pull the rope at opposite ends fosters tensions which may also be exacerbating Jay's own stress.

Both you and your husband share the wish for Jay to find acceptance. You feel that it would be achieved through a clean-cut appearance, while your husband points out that many teens today look a bit scruffy, and Jay would fit right in. It is not my mandate to decide which approach would yield the greater social benefit, but rather to support you in finding the compromise between Jay's social and emotional needs, as well as your own.

This brings me to the aspect of how you feel your image as a mother could be jeopardized if others judge you as neglectful. Of course, you have no way of knowing for certain that this is how you will be perceived, but even so, this concern must be balanced with your consideration of what may actually be best for your particular child and family thus allowing you to be more open-minded about the strategies you could employ with Jay.

You might, for example, consider your husband's point about de-emphasizing Jay's appearance and

permit Jay to sport a beard and longer hair, in terms of its emotional benefits. If you would be willing to move toward "good enough" rather than "perfect" grooming, this will help to reduce the strain of Jay's grooming routine and the pain that goes with it. (His hair and beard can be kept reasonably neat with far less intervention. Possibly he could wear a ponytail; his beard will need occasional trimming versus daily shaving.)

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*Finding a middle ground is associated with seeking balance and the need for compromise.*

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In seeking a middle ground, I'm sure you would agree that the use of a restraint even if you could apply it would be inappropriate. As you can see, there are many more humane and less anxiety-provoking options, such as the following:

- Encourage Jay to articulate what is bothering him about these procedures so that you can try to make them less aversive. Does it hurt for example because his nails are being cut too short? Is he annoyed by the sensation of the razor but more comfortable with an electric shaver?
- Offer incentives like a special reward, privilege or treat in return for his cooperation.
- Engage the services of an occupational therapist trained to work

with sensory integration dysfunction to help Jay build more tolerance to touch.

- Discuss with Jay's doctor the possible use of a mild sedative to help him relax before a major grooming session.
- Divide up grooming tasks so that Jay is not overwhelmed by having them done all at once and for too long.
- Invite Jay to feel a sense of control and self-pride by helping him to learn to take over more of his own grooming needs, like shaving.
- Take some time to explain to Jay what you will be doing and why. Devise a "social story" which you can review in preparation for grooming, or seek out a book for him geared to the subject.
- Consider taking a step back by hiring someone skilled at grooming and less emotionally involved to take over these functions.
- Suggest that your husband groom himself in front of your son and role model his own relaxed response while doing so.

*Do you have a question to Ask the Expert? Please send all queries to Veeta Engel at [efmagazine@miriamfoundation.ca](mailto:efmagazine@miriamfoundation.ca)*

**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 and is a consultant to Jewish Family Services.

# THE TIES THAT BIND

A documentary film that resonates with exceptional families

by EMMA LEGAULT

Few films are accurate in their portrayal of the life of an exceptional family in a way that resonates with parents of children with special needs. A National Film Board of Canada documentary stands out in its ability to do so. *The Ties that Bind* follows the Jordan family, Ottawa natives whose son Chris has cerebral palsy, mild developmental delays, Tourette syndrome and visual impairment, over a period of three years. The film explores many of the challenges that exceptional families face, capturing the incredible sacrifices that family members make in order to accommodate and support an exceptional child. In particular, it highlights the struggle both for Chris and his family in balancing his need to be taken care of and his need for autonomy.



*The Jordan family: Chris (center), L to R: Meredith, Geoff, Suzanne, Kathleen and Bill.*

Chris, 27, is an intelligent and articulate young man who refuses to

think of himself as “special”. He dislikes being surrounded by fellow exceptional people, preferring to disassociate himself from the labeling that defines them.

Despite his dependence on them for emotional, financial and instrumental support, Chris wishes to live away from his family. In their quest to help him achieve this goal, the Jordans consult an advocacy group in Ontario. They are matched with a facilitator who strives to help them put the necessary supports in place and Chris is forced to confront his own discomfort around other exceptional people as he attempts to create new friendships.

The family has its doubts as does Chris himself about the likelihood of his success in the transition away from them. They worry that he will be unable to sustain the secure network of friends, caregivers and resources necessary to go out on his own. Chris's father, Bill, is skeptical about whether he is up to the challenge observing that his son does not have any real friends. His older brother echoes these sentiments

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*Kathleen, Chris and Bill Jordan*

Kathleen have a remarkable bond. Kathleen's special knack for incorporating humor and for stimulating Chris's cognitive thinking, almost rivals the skills of any professional.

Throughout, the struggles of daily life are honestly and realistically depicted. Chris, who is



The film documents an unexpected turn of events when both Bill and Kathleen each need to undergo serious surgeries, adding additional challenges to the family. In the absence of one or the other parent the remaining family members display incredible restraint around their worries for Chris's sake. They work to preserve his daily routine in order to ensure his emotional stability so much so that they make the painful decision to defer their first visit to the hospital to be at their loved one's bedside post-operatively. When they finally do arrive at the hospital, they retire to the background enabling Chris to visit comfortably in the new environment.

Ultimately, Chris moves into a housing unit with several roommates where the family hopes he will learn independent-living skills. However, the placement is temporary and the Jordans continue to work on establishing long term living-arrangements.

*The Ties that Bind* is an honest, behind the scenes glimpse at real life in a family coping with exceptional challenges. It will inspire all who share the common goals of the Jordan family to provide for the protection and independence of their child. It is a film not to be missed.

*The Ties That Bind (2004) is available on DVD and VHS. For additional information visit [www.tiesthatbind-nfb.ca](http://www.tiesthatbind-nfb.ca) or contact 1-800-267-7710.*

*The Ties that Bind is an honest, behind the scenes glimpse at real life in a family coping with exceptional challenges.*

doubting that Chris will ever be able to have a girlfriend or family.

Nevertheless, it's apparent that the Jordan family is dedicated to helping Chris achieve his full potential. Chris is very attached to his parents and siblings who each serve as wonderful role models of appropriate social behavior. He and his mother



*Chris Jordan and John Ritchie, the Director of The Ties That Bind.*

easily upset by changes in his daily routine is deeply affected by the lack of continuity when support workers hired to provide some respite to his parents continually enter and exit his life.

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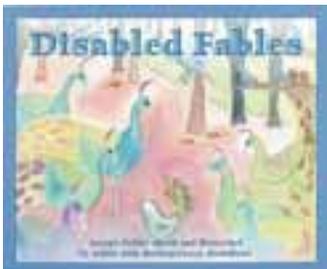
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# & Classics

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

## Disabled Fables

Aesop's Fables retold and illustrated by artists with developmental disabilities  
Star Bright Books Inc., 2004,  
56 pages, \$20.95



Glancing at the cover of *Disabled Fables*, it is almost impossible not to judge the contents of this book based on its introductory illustration of peacocks and blue jays, intricately drawn and painted in warm pastel colors that offer a taste of the beautiful paintings within. Even more remarkable than the artwork itself is the fact that it was painted by a woman who has a developmental disability. Thirty-five-year-old Helen Pacheo is a member of L.A. Goal, a non-profit organization in California that services adults with

*I get angry at work when other employees joke about me. One employee made a joke by telling me to mop the ceilings. This joke got me really upset so I told him to do his work while I did mine. I controlled my anger by not raising my voice because I could have lost my job. Losing my job would have been worse than getting stung like the bear [in the fable The Bear and the Bees].*

- *Disabled Fables*

cognitive challenges including autism, Down syndrome and mental retardation. Together with 11 other L.A. Goal members, Pacheo participated in an agency program where each was asked to choose a fable, recount it in their own words, illustrate it and relate it to their own experience.

In addition to fostering a sense of empowerment and independence in each artist, the program encouraged participants to retell stories in a proper sequence, rather than in disjointed segments, as some people with developmental disabilities tend to do. *Disabled Fables* is the product of the L.A. Goal program.

The superior creative talents of many of the artists surpass the skills of many "neurotypical" people. And as readers quickly learn, many of the contributors foster abilities and interests beyond art – a number also hold college degrees. While some of *Disabled Fables'* illustrations are less sophisticated than Pacheo's, all reflect the heartfelt dedication of their creators.

The most memorable portions of the book are the first-hand segments entitled "What this story means to me" in which many of the contributors

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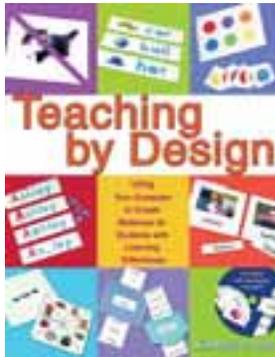
# CURRENTS & Classics

articulately convey their pain around being treated differently by others because of their disabilities.

*Disabled Fables* also includes a Foreword by actor Sean Penn who visited L.A. Goal in 2001 in preparation for his lead role in the movie *i am sam*. Penn's "seal of approval" is only an added bonus in a book that most certainly stands on its own.

## Teaching by Design

by KIMBERLEY S. VOSS  
Woodbine House, 2005,  
334 pages, \$48.95



Following the birth and diagnosis of her daughter Ashley with Down syndrome in 1984, Kimberley Voss was inspired to create educational

materials that would help Ashley and others with cognitive, sensory and physical disabilities to learn and flourish. Voss's efforts resulted in *Teaching By Design*, a comprehensive manual for parents and educators that teaches readers how to use their PCs and MACs to create custom-made tools for exceptional learners.

Designed for computer novices and pros alike, *Teaching By Design* is divided into three easy-to-follow components. In the first segment, Voss highlights the importance of controlling variables such as text, images, layout and media when designing and presenting programs for people with special needs. When discussing the use of symbols, for example, she underscores the need to be selective with their application and suggests that if a symbol of a book is used to represent the concept of reading, for instance, the same symbol should not be used to represent a library due to its potential to confuse the student.

In the second part, Voss delves into a variety of graphic programs, including Microsoft PowerPoint, AppleWorks,

CorelDraw, FreeHand, Illustrator and Paint Shop Pro and gives readers a mini-lesson in graphic designing.

Finally, *Teaching By Design* features step-by-step instructions and diagrams for over 40 materials including Lotto Boards, Flash Cards, Menus, Matching Games, Visual Schedules, Interactive Books and Telling-Time Worksheets geared to help teach language, math, communication, visual perception, reading, handwriting and self-help skills. A color photo insert at the back of the book features examples of finished products and an accompanying CD-ROM contains pre-designed templates to facilitate the tools' creation.

The highlight of *Teaching By Design* is Voss's heartfelt introduction in which she elaborates upon her daughter's challenges, her own feelings around Ashley's diagnosis and her commitment to help her thrive in spite of overwhelming physical, cognitive and emotional obstacles.

*Teaching By Design* is available through Monarch Books at [www.monarchbooks.ca](http://www.monarchbooks.ca)

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# What is so fragile about *Fragile X* syndrome?

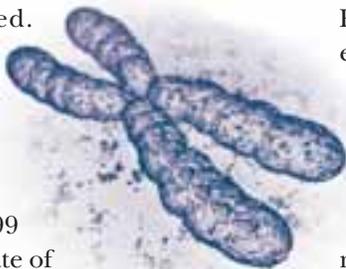
by KIM CORNISH, Ph. D.

**W**ith a prevalence of 1 in 3500 boys and 1 in 8000 girls worldwide, Fragile X syndrome constitutes the most common cause of hereditary developmental delay in children. (Girls diagnosed with the syndrome usually have milder levels of intellectual difficulties than boys, however.) Caused by an abnormal expansion of DNA just above the tip of the X chromosome's long arm, Fragile X occurs across every culture and is not related to the age of the mother at the time of conception.

## Diagnosis of Fragile X

In 1991, a DNA test called the Fragile X Mental Retardation - 1 (FMR-1) was introduced.

The test, which detects Fragile X syndrome with a 99 percent rate of accuracy, is routinely conducted on a blood sample. It is important that when one family member receives a Fragile X diagnosis, that the remaining family members be tested as well. It is especially important for carriers to seek



*This photograph of siblings Andrew, 9, & Katherine, 7, (both of whom have Fragile X syndrome), demonstrates how subtle the physical features of Fragile X syndrome really are.*

genetic counseling should they wish to bear children.

## How is Fragile X inherited?

Fragile X can be inherited from either parent who carries an abnormal copy of the gene on their X chromosome. Typically, carriers of Fragile X syndrome are themselves unaffected and experience neither intellectual impairments nor academic challenges. Since the Fragile X gene is on the X chromosome, a father cannot pass on any version of the gene to his sons; a father can only pass on a Y chromosome to his male offspring. A father can, however, transmit an X chromosome to his daughter, who will

consequently be a carrier of the gene as well. When the Fragile X gene (FMR1) is passed on from a mother to her children, the gene may become dramatically altered to the point where it is unable to work properly. When this happens the gene produces too little or none of the protein coded for it. Although the exact function of this protein is not yet fully understood, it is known to be critical to early intellectual and cognitive development.

## Autism vs. Fragile X syndrome: Ways in which the two overlap

Current research estimates that 15 to 25 percent of children who have Fragile X are often misdiagnosed as having autism due to the disorders' many overlapping features which include language-delays, echolalia<sup>1</sup>, and perseverative (repetitive) speech alongside poor eye contact and stereotypic movements such as hand-biting and hand-flapping. Many children are also overly-sensitive to environmental stimuli like sudden noises (e.g. sirens or alarms), movements, or changes in routine such as moving from one classroom to another. Anxiety provoked by sensory overload can often lead to hyper-arousal which in turn can lead to outbursts of aggression.

<sup>1</sup> Echolalia refers to repeating back words or sentences rather than responding to them. For example, if a child with echolalia is asked, "Is it sunny outside?" he may reply by saying, "Is it sunny outside."

## Autism vs. Fragile X Syndrome: Significant Differences

The physical features, social, behavioral and academic impairments present in people with Fragile X, differ from those in people with autism. Recognizing these features is critical in helping clinicians to properly diagnose the syndrome as early as possible so that effective educational and clinical interventions can be implemented from a young age.

### 1. Physical Features

Physical features that characterize the condition include an elongated face, large prominent ears and forehead and in males, macroorchidism (enlarged testicles) post-puberty. However, the wide variability in manifestation in both males and females, makes a diagnosis based on physical features alone almost impossible. It is precisely because of their “normal” appearance that many children are not identified as having Fragile X until relatively late in their development.

### 2. Social Impairments

In contrast to people with autism who often have difficulty relating to others and understanding the concept of emotions and empathy, people with Fragile X often express the desire to communicate and socialize with others, however their relationships can initially be hindered by extreme shyness. Once they begin to feel at ease with social partners, early social relationships can be quite rich and productive for children with Fragile X from an early age.

In addition, while many people with autism are severely impaired in their ability to understand the intentions

and beliefs of others, people with Fragile X have a greater potential to develop relatively good “theory of mind”<sup>2</sup> skills as they mature.

### 3. Academic and Behavioral Challenges

Both academic and behavioral challenges feature prominently in Fragile X syndrome, impacting on



Andrew at 6 years old.

both parents and teachers. The pattern and severity of these problems distinguishes them from other developmental disabilities. In the academic realm, some of the challenges particularly in males include:

- Delayed language-acquisition and repetitive (perseverative) speech.

- Weak short and long-term memory for abstract information such as mental mathematical calculations (like 2 x 6) can often lead to anxiety around mathematics.

- A lack of spatial awareness and visuo-motor coordination can often result in many children with Fragile X appearing clumsy and awkward.

- Difficulty maintaining attention over a long period for tasks that require abstract reasoning (such as math).

- Extreme difficulty performing sequential tasks (such as problem-solving tasks).

- Impulsive decision-making.

- The ability to becoming easily distracted in class by sudden noises, movements and routine transitions when attempting to focus on a given task.

In the behavioral realm, struggles co-existing with the academic ones affect both boys and girls as follows:

- Feelings of being overwhelmed by the demands created by social involvement, novel or unexpected situations and changes, even by the common transitions of daily life.

<sup>2</sup> ‘Theory of mind’ refers to the ability to understand the mental states and intentions of others and predict behavior.

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- Attention and hyperactivity problems, the severity of which often contribute to a clinical diagnosis of Attention Deficit Hyperactivity Disorder (ADHD).

## Educating a child with Fragile X

Recognizing that children with Fragile X syndrome have unique needs is crucial in helping them achieve their academic potential. At school, for example, a child who is easily distracted by other children and extraneous stimuli may benefit from a classroom with less stimulation and clutter and a desk placed away from the corridor where the sight of buzzing students may pose an added diversion. Utilizing visual reminders such as a timetable, symbols and photographs may give children a sense of predictability and control and reduce the anxiety that some experience during transition periods, such as when a teacher switches between one subject and another, or when students have to return to the classroom after recess. Additionally, presenting tasks in simple, bite-size chunks rather than sequentially will significantly help a child with Fragile X to remember an assignment and perform it successfully. Finally, as good imitators, people with Fragile X would certainly benefit from seeing other students model socially and academically appropriate behaviors and skills.

## Academic strengths

Particular strengths associated with Fragile X children include:

- Good verbal skills, especially receptive language and expressive vocabularies
- Strong short and long-term memory for meaningful information



*Katherine at 4 years old.*

(e.g., story-telling, objects, names) with a particular ability to tap into a repertoire of acquired knowledge and vocabulary.

- Strong visual memory. People with Fragile X also have good face-recognition and emotion-recognition skills.
- If an activity is meaningful and non-sequential and utilizes, for example, computer-based learning

techniques, people with Fragile X can focus for long periods of time without experiencing too much distraction or hyper-arousal.

## Communication between parents and educators

Effective communication between parents and educators is paramount if a child with Fragile X is to develop to his or her maximum potential. Often, parental expectations around a child's academic success exceed the child's actual performance and trajectory in the classroom. It is therefore important that parents and teachers collaborate to develop realistic goals and an Individualized Education Plan (IEP) in order to avoid potential disappointment. Above all, it is vital for all adults involved to recognize that every child's capacity to learn is unique.

While there are many internet resources available on Fragile X, few are uniquely Canadian and fewer still are bilingual. To meet this need, FXCARE (Fragile X Canada Research & Resource Unit) will be launched this summer. FXCARE is a web-based resource site that will be available in both French and English and specifically written with parents and teachers in mind. For additional information, visit [www.fragilexcanada.com](http://www.fragilexcanada.com) or [www.kimcornish.com](http://www.kimcornish.com)

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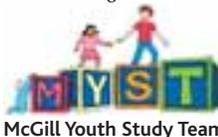
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**Dr. Kim Cornish** is a Professor and Canada Research Chair of Education and Neuropsychology in the Faculty of Education, McGill University, the Director of FXCARE and the Director of McGill's Child Laboratory for Research and Education in Developmental Disorders.

# Inspiration

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

*The bodies of the blind grow more and more conditioned.  
We rebound from the world, suck up the sting, and push ahead.  
It seems inevitable in our character to carry on,  
like the Terminators of this world. I defer to the wisdom of the blues.  
As my friend Harmonica Slim says, when I'm particularly bruised or gashed,  
"Well kid, you ain't good looking but you're hard to kill."*

- Ryan Knighton



*Ryan Knighton*

Author, editor, lecturer, published poet, co-founder of TADS magazine, person who is blind, college teacher of English, contemporary literature, pop-culture, rhetoric and creative writing, freelance writer, producer and performer of radio monologues and documentaries about blindness for the CBC, husband, car aficionado, "comedian"

# Life Plan Essential #2: Compile a list of instructions for future caregivers

*EF presents the second article in its exclusive four-part series on  
Creating a Life Plan for Children with Special Needs*

by JOHN DOWSON, Ch lp

A comprehensive Life Plan includes a Lifetime Lifestyle Needs Plan, which basically comprises a detailed list of instructions around your child for his or her future caregivers. In many ways, planning for your child's future lifestyle needs is similar to preparing to go away on a trip, except in the former case you're leaving with the knowledge that you're not going to return! Think back to a time when your child was young and you were planning to go out for the evening or away for the weekend. What instructions did you give to the person who looked after your child? Chances are you informed the caregiver about your child's bedtime, the type of food he liked for his evening snack, how she liked to be tucked in, any medication he may have been taking and how it was to be administered, any special behaviors or needs that the caregiver ought to have been aware of and who to contact in case of an emergency.

By the same token, it is important to give your child's future caregivers a similar list of instructions so that they will know how to properly care for your son or daughter according to his or her specific needs.

I am reminded of a meeting I recently had with an exceptional



---

*Everything you know about your son or daughter's special needs, preferences and dislikes and the many other elements that comprise his or her daily life and activities will die along with you unless you transfer them to your child's future caregivers, trustees and guardians.*

---

family who was interested in creating a Life Plan for their 27-year-old daughter, Emily. After reviewing her family's circumstances, the girl's mother concluded, "What I'm really worried about is what's going to happen to Emily after her dad and I are gone." To which her married son, who was present with his wife, replied, "Don't worry mom, Helen and I will look after Emily. We know

her." Rather than being reassured, Emily's mother exclaimed, "You don't know Emily at all! You're only here on the weekends!"

As with Emily's case, while your child may have a rapport with a number of relatives, friends, caregivers and support workers who may be suitable to care for your child after you've passed away, chances are you know your child better than anyone else – having spent the most consistent time with him or her since birth.

As such, everything you know about your son or daughter's special needs, preferences and dislikes and the many other elements that comprise his or her daily life and activities will die along with you unless you transfer them to your child's future caregivers, trustees and guardians. Compiling an explicit list of instructions for your child's future caregivers will help to ensure that he or she will lead as happy, healthy and independent a life as possible after you are gone.

When developing your child's Lifetime Lifestyle Needs Plan you may wish to consult with your child (if possible), other family members and any community support workers who know your son or daughter well. Although the plan you devise

is not an official legal document and does not form part of your last will and testament, it is just as important as your last will and testament.

A detailed Lifetime Lifestyle Needs Plan is an invaluable guide to your child's future caregivers, trustees and guardians. It can be formal and



generalized (i.e., "To Whom It May Concern"), or addressed to a specific individual. Moreover, it can be handwritten, typed, burned on a CD or DVD, or recorded on an audio or videotape.

Be sure to include the following basic information in your list:

- Your child's full legal name (and any nicknames he or she may go by), date of birth and social insurance number.
- Names of relatives, friends, guardians, trustees and others with whom your child has a special relationship and or who may have participated in your final arrangements.

- Your child's detailed medical history including any seizures, speech or mobility issues, names of physicians, dentist and therapists, allergies, medications and how they are administered, over-the-counter drugs and decisions around birth control.
- Information about yourselves - the child's father and mother - and your marital status, your siblings, or the child's siblings' names and ages and their home addresses, phone numbers and e-mail addresses.
- Your child's current and past living-arrangements, what worked and what didn't and any plans you have made or envision for your child's future living arrangements.
- Your child's Individual Education Plan (I.E.P), and his or her daily-living and self-care skills, including his or her ability to care for personal hygiene and dressing. Who decides what your child wears?
- Any domestic activities that need to be performed for your child, like shopping, cooking, house-keeping and laundry.
- Your child's needs around transportation, education, day programs, social and recreational activities.

- Which religion your child belongs to, if any. List any religious leaders, and the extent of your child's participation. List the rights and values that should be accorded your child and an overview of your feelings and vision for your child's future.
- Any finances and assets, bank accounts, expenses, wills, safety deposit boxes, life insurance policies, details around your funeral and whether it has been pre-paid, income tax information and any trusts. Include the names, addresses and phone numbers of all advisors such as lawyers, accountants and financial advisors, and a list and location of all pertinent documents and records.

While only one parent may want to do the actual writing, both may wish to sign the Lifetime Lifestyle Needs Plan. Make multiple copies of it, hold a family meeting and review the plan with your child if possible and all of your child's future caregivers. Place a copy of your child's Lifestyle Needs Plan and any accompanying documents such as birth certificates, Medicare cards and passports in a secure place and put a second copy in a binder or folder where it can easily be accessed and reviewed. Update your child's Lifetime Lifestyle Needs Plan should his or her circumstances change. You may only need to revise certain pages and not the entire document.

Finally, remember that parents don't plan to fail they just fail to plan!

**John Dowson**, Ch lp, is the Executive Director of LifeTRUST Planning, a national company that serves exceptional families across the country.

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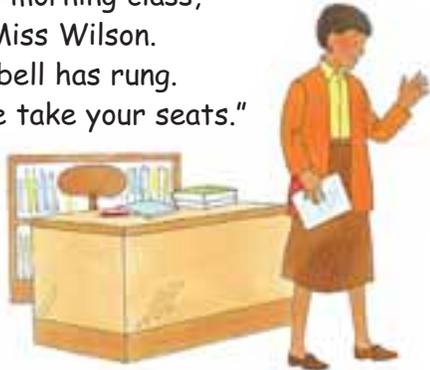
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# An introduction to the Hidden Curriculum



"Good morning class,"  
said Miss Wilson.  
"The bell has rung.  
Please take your seats."



"Where should I take my seat?"  
asked Amelia Bedelia.  
"Should I take it out  
to the playground?"



- *Amelia Bedelia  
Goes Back to School*,  
by HERMAN PARISH

by AVIVA ENGEL

Of the hundreds of fictional storybook characters that have emerged over the years, few are as memorable and beloved as Amelia Bedelia, the bewildered housekeeper from the series that bears her name who executes all instructions exactly as they are given. Whether at a baseball game where she literally steals the bases or in the kitchen where she actually dresses a chicken, Amelia Bedelia's only salvation in a world where social acceptance is contingent on the ability to understand symbolic language is her endearing personality.

---

*Amelia Bedelia's  
ignorance of social rules  
and inability to grasp  
figurative language  
typifies many real people  
with ASD, who do not know  
the "Hidden Curriculum."*

---

Although Amelia Bedelia is the imaginary brainchild of authors Peggy and Herman Parish, her ignorance of social rules and inability to grasp figurative language typifies many *real* people with Autism Spectrum Disorder (ASD), who do not know what renowned clinician and author<sup>1</sup> Dr. Brenda Smith Myles calls the "Hidden Curriculum" – knowledge that is not formally taught to "neurotypical" children and youth, but is acquired via incidental learning.

"The Hidden Curriculum is a set of unwritten rules that everyone knows," explained Smith Myles at a recent conference in Montreal sponsored by the Miriam Foundation's Abe Gold Learning and Research Centre. "It comprises any information that seems obvious, or assumed and it's so important because violation of these rules can render a

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<sup>1</sup> Dr. Smith Myles is the author of numerous books, including *The Hidden Curriculum: Practical Solutions for Understanding Unstated Rules in Social Situations* (Shawnee Mission, KS: Autism Asperger Publishing Company, 2004) which she co-wrote with M.L. Trautman and M.L. Schelvan.



person a social outcast,” said Smith Myles, an associate professor in the Department of Special Education at the University of Kansas and co-director of the department’s Asperger syndrome and autism graduate program.

### The Hidden Curriculum’s many applications

According to Smith Myles, the Hidden Curriculum’s application varies depending on the age, gender and culture of the person you are teaching. The curriculum aims to teach children and adolescents with ASD skills that will facilitate successful social interactions with different people in various environments. It also teaches daily-living and problem-solving skills and strives to help children acquire self-awareness and self-respect.

“Children with ASD tend to generalize what they are taught in every situation,” she said. “They need to understand that the Hidden Curriculum varies depending on different situations and environments. The way you interact with colleagues is different from the way you interact with peers, and the way a child interacts in the classroom is different from the way he interacts on the schoolyard.”

---

*The way you interact with colleagues is different from the way you interact with peers, and the way a child interacts in the classroom is different from the way he interacts on the schoolyard.*

---

In fact, one would be hard-pressed to find an environment where knowledge of the Hidden Curriculum is unnecessary. As Smith Myles pointed out, unwritten social rules apply at home and school, at the library, when dating, at restaurants and theatres, at camp, at public swimming pools, restrooms and showers, at work and in doctors’ waiting rooms – to name a few.

“There’s even a Hidden Curriculum around the legal system,” said Smith Myles. “People with ASD are seven times more likely to come into contact with the legal system than neurotypical individuals. Yet this is an area that we do not teach [people with ASD to deal with appropriately]. I know a man with ASD who had been speeding and was pulled over by a police officer. The officer asked him for his registration and driver’s license, which the man gave him. The officer went back to his vehicle and the man drove off. He thought the transaction was over. The officer did not say ‘please wait here’, because that was assumed knowledge. A police chase ensued and luckily no one was hurt.”

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Our goal is to help exceptional individuals integrate into the community and assist them to live socially-active, productive lives.

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](http://www.miriamfoundation.ca).



## Unwritten social rules for children and adolescents

For children and adolescents, the classroom represents a particular setting where ignorance of the Hidden Curriculum can have profound repercussions on a student's social and academic success. "If a teacher [tells a student] 'Becky, stop talking', a child with ASD will start talking. And when he starts talking, he [gets] disciplined. He thinks the teacher's unfair, because when the teacher said 'Becky stop talking', he didn't understand it to mean everyone in the class stop talking."

Smith Myles also gave examples of the Hidden Curriculum's relevance

to adolescents. "Children with ASD are taught, you go to the library to get a book. If you want to talk, you speak quietly. When you are a teenager, going to the library is a major social activity. Books have nothing to do with it. You're there until it closes and somebody's parent has to pick you up, or you're kicked out. How loudly do you talk? As loudly as you can without being kicked out. Teenagers with ASD need to understand the unwritten rules for going to the library with peers."

## Examples of Hidden Curriculum Items to teach children with ASD for school, from Dr. Brenda Smith Myles:

- If one small incident occurs and the teacher corrects you, it does not mean the entire day is bad.
- You should talk to teachers in a pleasant tone of voice because they will respond to you in a more positive manner.
- If a teacher gives you a warning about behavior and she wants you to stop, you're probably not going to get in trouble but if you keep doing the behavior, you're probably going to get in trouble.
  - Do not tell a teacher he or she smells and needs to wear deodorant.
- When a teacher tells another student to stop talking, it is not a good idea to start talking to your neighbors, since the teacher already expressed disapproval of that action.
- Not all teachers have the same rules for their class.
  - When someone else is getting in trouble it is not the time to show the teacher something.

Amusingly, Smith Myles also touched upon the Hidden Curriculum for teenagers around cursing in school. "And that is, look around first," she said. "If there is an adult [present], do not curse. I am not advocating cursing. But what happens is that children with ASD quite often get caught cursing more than their neurotypical peers. And it's probably not to say they're cursing more than their peers, it's just that they are letting loose with this flow of colorful words without understanding that they shouldn't be doing it in front of adults."

## Precautionary Measures

Despite the sensitivity and humorous nature of many of the items that comprise the Hidden Curriculum, Smith Myles emphasized the need for children and adolescents with ASD to learn accepted protocol in places like public restrooms and showers particularly as safety precautions. "What's the first thing we

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### NATUROPATHIC AND HOMEOPATHIC MEDICINE FOR AN EFFECTIVE APPROACH TO:

<ul style="list-style-type: none"> <li>• AUTISM</li> <li>• PDD/NOS</li> <li>• SENSORY ISSUES</li> </ul> <p style="text-align: center; font-size: small;"><i>Insurance Receipts Available</i></p>	<h4 style="text-align: center; text-decoration: underline;">Services Provided</h4> <ul style="list-style-type: none"> <li>• DAN! Protocol</li> <li>• Certified Clinical Nutrition</li> <li>• Functional Medicine</li> </ul>
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**(514) 695-2112**

1 Holiday Avenue, Suite 440,  
West Tower, Pointe-Claire, Quebec



teach kids with ASD? We teach sustained eye contact to ensure that we know they are listening. When a child gets into a situation where he or she is showering in a group setting, he or she will sustain eye

have the potential to be victimized. That's very serious."

Similarly, Smith Myles highlighted the dilemma of children and adolescents with ASD learning social rules primarily from female educators. "Most children with ASD are boys and most are taught social skills by women who don't know men's cultural and social rules and interactions. For women, going to the bathroom is a social occasion. When we get there we will talk. Men do not talk in the bathroom and do not orient towards each other. Boys need to learn appropriate social behavior from men."

Because the Hidden Curriculum comprises innumerable lessons that need to be taught, Smith Myles recommends that educators and parents strive to introduce one new Hidden Curriculum item daily. "At school, you can identify one Hidden Curriculum item, write it on the board and spend the first two minutes of class talking about the rules. At home, if parents select one Hidden Curriculum item per day, you will cover 365 per year. Grab the teachable moment. If you're at the mall and you're a man with your son and you're going into the men's room, spend some time talking about it and draw some actual pictures so the child understands what it is he's supposed to do. Model the appropriate behavior." ■

**Dr. Brenda Smith Myles recommends the following books to help teach the Hidden Curriculum:**

- **Bringing Up Parents: The Teenager's Handbook** by ALEX J. PACKER, Ph.D.
- **How Rude! The Teenager's Guide to Good Manners, Proper Behavior and Not Grossing People Out** by ALEX J. PACKER, Ph.D.
- **The Amelia Bedelia Treasury** by PEGGY PARISH
- **A Little Book of Manners for Boys** by BOB and EMILIE BARNES
- **No B.O.! The Head-to-Toe Book of Hygiene for Preteens** by MARGUERITE CRUMP
- **As a Gentleman Would Say: Responses to Life's Important (and Sometimes Awkward Situations)** by JOHN BRIDGE and BRIAN CURTIS
- **The Care and Keeping of You: The Body Book for Girls** AMERICAN GIRL LIBRARY
- **A Little Book of Manners: Courtesy and Kindness for Young Ladies** by EMILIE BARNES

*Most children with ASD are boys and most are taught social skills by women who don't know men's cultural and social rules and interactions.*

*Boys need to learn appropriate social behavior from men.*

contact," said Smith Myles. "A boy with ASD, who we have taught to be social, will orient toward an adult male in the men's room. What if the man is a sexual offender? The behavior communicated by the child tells him he has a victim, because he knows that that boy does not know the rules. And if someone tells a child with ASD not to tell [about having been abused] he will not. Children who look different

**PARENT SUPPORT GROUP** for parents of children with Special Needs

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- Do you want to share your experiences with other parents?
- Do you want to get support from other parents and professionals to help you with

the daily struggles of dealing with your special child?

- Do you want a night out to celebrate the successes of your Special Needs child with those who can appreciate these achievements?

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**Abby Kleinberg-Bassel, B.A., M.Sc., Ed.**  
Special Needs Consultant

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# Sure I can

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



## *What's in a Word?* *Fair Portrayal vs. Political Correctness*

by MICHAEL LIFSHITZ

**I** am crippled. I am handicapped. I am physically-disabled. I am physically-challenged. I am a person with a disability.<sup>1</sup> Come to think of it...what in the heck am I? What should I be called? Well, frankly my preference would be Michael, but since we live in a society where everyone and everything seems to have a label, I guess I have no choice but to go with the flow.

Over the years, many words and euphemisms have been used to describe someone who has a disability, including “different”, “unique”, “special” and most recently, “exceptional” (case in point: *Exceptional Family*—no disrespect intended to my Editor!). In an effort to set the standard of political correctness and inclusion, Social Development Canada published a terminology guide in 2003 called *A Way with Words and Images*<sup>2</sup>, geared largely for journalists as a guideline when reporting and portraying people with disabilities in the media. However, my question is does it really make a difference what we call people with disabilities? Does it really matter what word we use, or is it simply a question of political correctness? To find the answer, I thought I’d explore what these words really mean in greater detail. So I broke out the dictionary<sup>3</sup> and took a look!

### ***Crippled***

- 1: deprived of the use of a limb and especially a leg*
- 2: deprived of capability for service or of strength, efficiency, or wholeness*

Now, if anyone was to call me a cripple, I would probably slap them upside the head, the definition is accurate to some degree. My disability (to use the common term) does deprive me of strength and use of my legs. However, it certainly doesn’t render me inefficient or “unwhole” in any way. Furthermore, the problem is that the word *crippled* took on an offensive and derogatory connotation as individuals increasingly applied it to whole persons (i.e. You are a cripple; therefore incapable of service) as opposed to the specific body part in question (i.e. Your leg is crippled; therefore it specifically is incapable of being of service, at least to some degree.)

### ***Handicapped***

- 1: put at a disadvantage*

While the term *handicapped* is still frequently employed in many circles, it too has been dismissed as an inappropriate label due to its politically-incorrect, offensive overtone. Like the term *crippled*, it too refers to the generalization of an entire person rather than the particular

issue he or she is facing. Does my disability put me at a disadvantage? It depends on what we are talking about. If you are asking me to run a marathon, yes, I am at a pretty big disadvantage. However my disability has absolutely no bearing on my ability to achieve scholastically, my ability to work efficiently as an accountant, my ability to have relationships with peers, friends or members of the opposite sex.

Moreover, the term *disadvantaged* is also applied when describing certain demographic groups, like people living below the poverty line, for example. Does that make living in poverty a type of handicap? Does that mean that people living below the poverty line are equally eligible to receive stickers enabling them to park in accessible parking spots?

### ***Disabled***

- 1: to deprive of legal right, qualification, or capacity*
- 2: to make incapable or ineffective; especially: to deprive of physical, moral, or intellectual strength*

Upon reading this, I suddenly realized why many people view those of us with disabilities as incapable or inferior. Based on the above definition, once someone has a disability, they are seen as incapable or ineffective.

1 For those of you who didn’t read my introductory article (and if you didn’t, what were you thinking?!),

I was born with a condition called Multiple Congenital Musculoskeletal Abnormalities.

2 [http://www.sdc.gc.ca/en/hip/odi/documents/waywithwords/09\\_terminologyGuide.shtml](http://www.sdc.gc.ca/en/hip/odi/documents/waywithwords/09_terminologyGuide.shtml)

3 All definitions are taken from the Merriam Webster Dictionary Online <http://www.m-w.com>

While I am the first to concede that I have difficulty or am incapable of doing certain things (rock climbing for one), there are plenty of things that I am capable of doing. So again, the term *disabled* seems to be both an inappropriate and unfair label.

### **Challenged**

*1: to make or present a challenge*

While this term screams political correctness, it is far from accurate in my view; asking someone to climb Mount Everest is a physical challenge. Solving a complex math problem might be intellectually-challenging for some. Every one of us faces challenges on a daily basis. Life is a challenge. Does that mean we all have a disability? While there are those who argue that everyone has some sort of disability (using disability to mean some sort of weakness/issue), I have a problem with that argument: If everyone has a disability, where the heck am I going to park at the mall?

Just a tad discouraged in my quest, I decided to delve into the terminology put out by Social Development Canada. Their advice: Don't refer to someone as disabled, but rather as a *person* with a disability.

Wow...I am a person. There is a novel concept. Maybe they are on to something here... I am a person with a disability. In the same way that I have brown hair, or green eyes, I have a disability. It is just another part of me. Yes, it does affect me, but it does not define me. That is the whole point I try to make to people daily. I am more than just the disability... I am a person... with a disability. ■

# Insights

A compilation of upcoming  
community events of interest

## **ONGOING Special Needs Network**

*Montreal's Special Needs Network offers confidential support, information and advocacy for exceptional families, caregivers and professionals.*

2100 Marlowe Ave., 5<sup>th</sup> Floor,  
Montreal, QC. Free. (514) 736-2273  
or (877) SNN-AIDE outside  
of Montreal or [snn@yaldei.org](mailto:snn@yaldei.org)

## **ONGOING: Children Sought for Integrated Play Group**

*Montreal's Yaldei Developmental Centre is recruiting "mainstream" children and children with autism ages 4-7 to join an exciting after-school play-group that will integrate "expert" and "novice" players in order to encourage appropriate social and play skills and friendship-building.* Information:

Leila Suckewer or Fiona Smith  
@ (514) 279-3666 ext. 241 or  
[leilas@yaldei.org](mailto:leilas@yaldei.org)

## **AUGUST 22-26: World Down Syndrome Congress**

*The 9th World Down Syndrome Congress invites individuals with Down syndrome, their families and professionals to discuss issues including advocacy, education, health, social policy and more. The Canadian Down Syndrome Society will be sponsoring two events during the Congress: the World Advocacy Day (co-sponsored by the CDSS and the National Down Syndrome Society) and the CDSS Dinner and Dance, a celebration to close the Congress events.* Vancouver Convention and Exhibition Centre, 999 Canada Place, Vancouver, B.C. Students: \$160, Professionals: \$575, Family Members: \$400, Participants with Down syndrome/Siblings (ages 13 and up): \$120, Children's Program (5 years and up): \$140. Information: (604) 681-5226 or visit [www.wdsc2006.com](http://www.wdsc2006.com) and [www.cdss.ca](http://www.cdss.ca).

## **SEPTEMBER 9-10: 47<sup>th</sup> Annual Outdoor Art Exhibition and Sale**

*The West Island Association for the Intellectually Handicapped (WIAIH) in conjunction with the Lakeshore Association of Artists presents the 47th Annual Outdoor Art Exhibition and Sale. One-third of the sales will be donated to WIAIH. Entertainment & refreshments.*

10 a.m. to 5 p.m. Pointe-Claire Cultural Centre, Stewart Hall, 176 Lakeshore Road, Pointe-Claire, QC (Parking available at the Plaza Pointe-Claire 269 St. John's Blvd with shuttle service to and from Stewart Hall)  
Information: WIAIH @ (514)694-7090.

## **OCTOBER 25- 27 Autism 2006 - Geneva Centre for Autism International Symposium**

*The Symposium will provide a cross-section of perspectives on the most recent research and information on evidenced based best practice.*

*Topics include bio-medical and neuro-biological research, IBI, social skills, communication, Asperger's Disorder, and more. Speakers from Canada, U.S., Great Britain, and Australia.*

Oct. 25: Registration 7:30 a.m., sessions 9-4: Registration 6:30 a.m., sessions 9-5. Metro Toronto Convention Centre, 255 Front Street West, Toronto, ON. Parents: \$150-\$495, Professionals: \$295-\$700. Information and registration: Ginny Kontosic @ (416) 322-7877 ext. 516 or [symposium@autism.net](mailto:symposium@autism.net) or visit [www.autism.net](http://www.autism.net).

### **EF welcomes your Insights!**

To publicize an upcoming community/non-profit event in your area **FREE** of charge – contact us at [efmagazine@miriamfoundation.ca](mailto:efmagazine@miriamfoundation.ca). All information will be subject to the discretion of the editor and publisher.



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