

Exceptional

Vol. 6 No. 3 • Spring 2011

CANADA'S RESOURCE
MAGAZINE FOR PARENTS
OF EXCEPTIONAL CHILDREN

Family

This is our
**FINAL
ISSUE!**

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**LIFE AFTER
DIVORCE**

**Making
Waves**
across Canada

**Singer
Denis
Harting**

A novel way
to explain CdLS

**Debunking
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PHOTO: JULIAN HABER

ON THE COVER: Joined at the hip: Montrealers Theah Porritt, 6, and her instructor, Larah Maunder, take part in Making Waves, a national, student-run swim program.

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Exceptional Family

Vol. 6 No. 3 Spring 2011

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**Exceptional Family is an initiative
of the Miriam Foundation.**



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ISSN 1715-4901

Legal deposit, Library and Archives Canada, 2005

Legal deposit, Bibliothèque nationale du Québec, 2005

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PUBLISHER'S NOTE

Embracing the Digital Future

There's no disputing that the advent of smart phones, e-readers and tablets has forever altered the way we access media – and in particular, the printed word. A recent study on consumer attitudes about digital magazines conducted by the Harrison Group (2009 Consumer Research) reveals that 86% of current print magazine readers expect to be reading digitally within the next 12 months.

Digital media is the wave of the future. This reality, combined with the Miriam Foundation's resolve to go green, cut costs, provide information in both French and English, and expand our global reach, have contributed to our decision to stop publishing Exceptional Family magazine. This is our last issue.

We extend our sincere thanks to the Exceptional Family team – editor Aviva Engel and marketing manager Julie Klucinkas – for their dedication to delivering the authoritative and inspirational content that has earned your endorsement and respect since 2005.

The Miriam Foundation remains committed to being Canada's resource for parents of exceptional children. In the future, we will deliver on this commitment through our website at the Miriam Foundation. We invite you to email us at info@miriamfoundation.ca and register to become a member of our community.

If you are a current Exceptional Family subscriber, we will be contacting you about your subscription in the coming weeks, and will supply you with information on next steps.

We hope you will join us as we ride the digital wave.

Yours Truly,



Warren Greenstone
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FROM THE EDITOR

It's All about Attitude

There's a powerful motivational poster designed by the Successories® company around the theme *Attitude*. A photo captures “an impressive display of unstoppable energy” during a storm, as “lightning brilliantly illuminates the sky turning night into day” (so the description reads). The message below it proclaims, “Our lives are not determined by what happens to us, but by how we react to what happens; not by what life brings to us, but by the attitude we bring to life. A positive attitude causes a chain reaction of positive thoughts, events and outcomes. It is a catalyst...a spark that creates extraordinary results.”

While the visual certainly makes for terrific wall art, the caption could also be paired with the pictures of a number of people featured in this issue. People like Quebec singer Denis Harting, an exceptional father, who greets every new day with enthusiasm and hope despite an accident that left him blind in infancy, a difficult upbringing, and the loss of a child in later life (page 44). People like Nathalie Wendling (page 34), Barb De Roo and Simon Rayment (page 47), who were inspired by their children's diagnoses to assist and educate others. And people like Sandi Graham McWade (page 30) and Donna Long (page 38), who had the courage to get in touch with their emotions, and the strength to rise up from their grief to places of acceptance and joy.

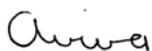
These people truly personify the poster's message. They *live* the poster's message, every day. Every day, they put one foot in front of the other and persevere, embracing optimism in spite of adversity, uncertainty and, sometimes, even pain.

Parenting an exceptional child is not without challenges. Life is not without challenges. But life is always a matter of alternatives. These people consciously choose to channel their energies into positive sparks. It's the attitudes they bring to life – not what life brings to them – which enables them to turn darkness into light.

I'm a huge fan of motivational paraphernalia and of Successories® products in particular (no, I'm not getting a commission).

But lightning storms?!

They've got nothing on these folks.



Aviva Engel
editor@exceptionalfamily.ca



PHOTO: JULIAN HABER

STROKE OF GENIUS:

Swim Program is *Making Waves* across the Country



PHOTO: JULIAN HABER

Instructor Waka Hayakawa and Leah Hamaoui, 4, in Montreal.

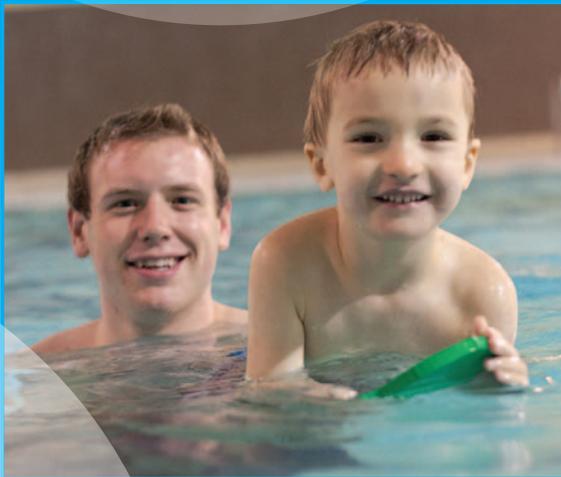


PHOTO: MICHAEL GARFINKLE

Instructor Christopher Hewison and Alexander Zetka-Pettigrew, 5, in Montreal.

Student volunteers give of themselves for exceptional kids' sake – and are gratified in return

by WENDY HELFENBAUM

If the first image that pops into your mind when asked to picture a university student on an early weekend morning is someone sleeping off a long night of partying or an all-night cramming session in the library, then the images and stories on these next few pages will likely surprise and inspire you.

A medical student in Halifax helps a young boy with Asperger syndrome to overcome his paralyzing fear of the water; a university student in Hamilton builds a trusting relationship with a child who has significant developmental delays; and a graduate student in Montreal tirelessly develops a vision focusing on the power of students at Making Waves, who are also making enormous differences in the lives of exceptional children.

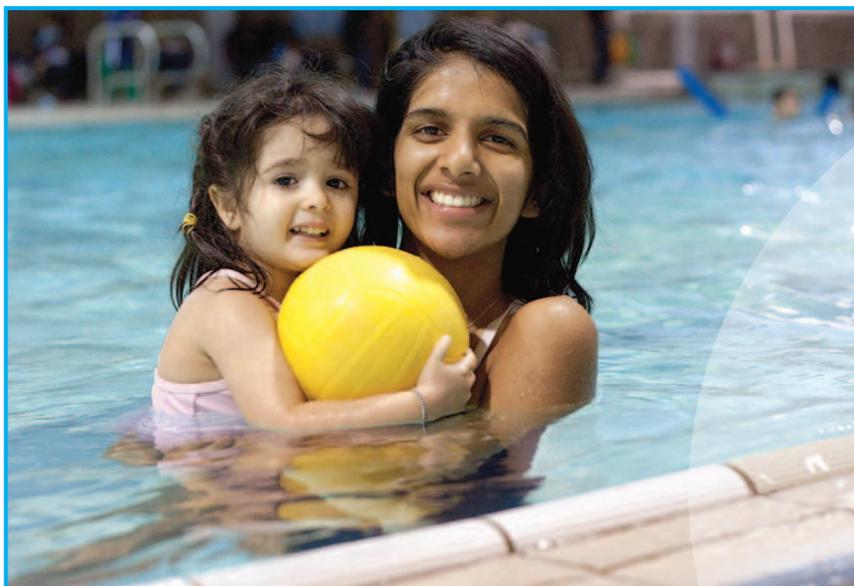
In 2004, a group of undergraduate students from Montreal's McGill University came across some startling statistics: a 2002 study by the Centre for Disease Control and Prevention found that drowning is the second-leading cause of injury-related death in children, despite a significant increase in general swimming proficiency in North America. Another study, reported in 2001 in *Injury Prevention*, had found that children with special needs are ten times likelier to suffer from a submersion (water-related) injury than the general population.

Buoyed by a desire to make a difference

The students formed BlindSwim, an organization that ran from 2004-2005 with a mission to help children with visual impairments learn to swim. Matthew Morantz, 24, joined up in 2005, changing the group's name to Making Waves Canada and widening its reach to include children with cognitive and physical disabilities, from autism to hearing impairments.

"Making Waves grew out of the frustration with the current system, where children are taught swimming in groups," explains Morantz, Making Waves Canada's executive director and a McGill graduate student. "Group lessons are quite affordable for the typical child. But the kind of attention that a blind child needs, for example, is much more intense."

Morantz says that because instructors typically use their voices to communicate with a child who is underwater while demonstrating swimming strokes, that technique is "not at all suitable for working with a blind child; one instructor can't physically move or manipulate several children [with visual impairments] at a time."



PHOTOS: MICHAEL GARINKLE

Instructor Mathura Ravishankar with Alessia Panaccione, 4 (holding ball), and instructor Cameron Oliver with Ilona Worms, 3 (wearing life jacket), in Montreal.

Many children with special needs require expensive private lessons that are all but out of reach for most. A set of nine group swimming lessons for children at a community pool typically costs about \$100, while private lessons cost nearly four times as much, notes Morantz. "So the children that need this service the most, and who are most at risk for drowning or water-related injuries, are the ones that are not getting water-safety education. The idea that a family with [an exceptional child] would have to pay more

just seemed ludicrous to us. Our main objective is to provide swimming lessons that they couldn't otherwise afford," says Morantz.

Run entirely by student volunteers, Making Waves charges \$20 for nine, 30-minute private lessons. The program, which accepts children ages three-and-a-half to 15, runs two sessions of weekly lessons from September to late spring. In 2005, five children enrolled in the program. The student instructors marketed their services through word

of mouth within the special needs community. Today, 50 children are registered in Montreal. “At first, it was hard to find volunteer instructors, but this year, we had 180 applications for 40 spots,” reports Morantz.

Expanding across Canada

Encouraged by the success of the Montreal program, Making Waves opened a Hamilton chapter run by McMaster University students in 2009, followed by ones in London, Ottawa, Halifax and the Okanagan Valley. More than 300 Canadian children took swimming lessons in 2010 through Making Waves.

“By engaging students in their communities, we’re contributing to the personal growth of instructors, to the community [and to children’s] life-long health,” says Morantz.

Volunteers key to program’s success

Kyle Jewer became an instructor at Making Waves Montreal in 2008, and is now president and founder of Making Waves Halifax. “The thing I love about Making Waves is that it is entirely volunteer-run,” says Jewer. “The instructors receive nothing in return for their involvement, aside from the satisfaction of having done something good for someone else, and they’re grateful for the opportunity.”

When Jewer began medical school at Dalhousie University, he and fellow classmate Rachel Shaw launched the Halifax chapter and recruited volunteers. “We were very fortunate to receive funding from our alumni association and had a great deal of support from community pediatricians and early interventionists,” says Jewer. “The first session was very well received, and our enrolment nearly tripled for our second set of lessons [last] fall.”



PHOTO: ALISON POWER

Making Waves Halifax coordinators Rachel Shaw and Kyle Jewer, at Halifax’s Centennial Pool.

“Teaching a child to swim is always rewarding, and this is especially true when the child has special needs,” says Jewer. “We learn a great deal from our experience as well: communication skills and an appreciation for the challenges faced by families with a special needs child.”



Shortly after Tricia Schneider, a former instructor with Making Waves Montreal, began graduate school at McMaster University, she became president of Making Waves Hamilton. “Initially, I wanted to give back to the community and I knew that my prior experience as a swim instructor would be an asset,” recalls Schneider. “It wasn’t until I began giving lessons that I realized the importance of the program. Seeing firsthand how difficult it was for children to learn aquatic skills that I previously took for granted solidified that what we were doing was important – providing children with disabilities the opportunity to learn skills that could one day save their lives.”

Last fall, a concerned parent was so sure her son wouldn’t get near the water that she wondered whether to even bring a bathing suit. “I told her to [put his suit on] at the start of the lesson even if we couldn’t get him in the water,” recalls Schneider. “Her son got in the pool at the beginning of the lesson and stayed in the entire time, because his instructor established trust and friendship right from the start. Watching this relationship blossom over the course of the session was heartwarming.”

Grateful parents

Four-year-old Leah Rose Hamaoui of Montreal has Angelman’s syndrome, which is characterized by severe developmental delays. She cannot speak and probably never will. She has just begun to walk on her own. But in the water, Leah thrives.

Leah’s mother, Lisa Hamaoui, particularly appreciates Making Waves’ dedicated instructors. “They help because they want to, and they take time out of their lives to help children

MESSAGE TO SUBSCRIBERS



This is the last issue of Exceptional Family.

If you have a paid subscription, we will be contacting you by mail in the coming weeks with information on next steps.

Should you have questions or concerns in the meantime, contact us:

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PHOTO: MICHAEL GARFINKLE

Instructor Clair Wilmot and Jawad Kazan, 5, make waves in Montreal.

“Here, children can relate to one another and parents are able to network and form friendships as well.”

who really need it. The price is also something that cannot be ignored. Raising a special needs child is very expensive, and we appreciate any help we get. To have a top quality swimming program for \$20 per session is just amazing.”

Mikhail Ryan-Sawler, 10, was born at 22 weeks weighing 780 grams. He has cerebral palsy and severe myopia for which he wears bifocals. Mikhail is able to walk independently, but uses a walker and a wheelchair for distance.

“We signed up for Making Waves because Mikhail was very fearful of the water and needed more exposure to swimming,” explains Mikhail's grandmother, Wanda Ryan, who shares parenting duties in Halifax, with his mother Dawn. “It was imperative that he have one-on-one in the pool and be paired with someone who recognizes and respects his fears. We hoped that this would help him to overcome his apprehension in the water and over time

he'd become more relaxed and enjoy the experience, and that's precisely what happened in the second session. Mikhail's instructor's tolerance, enthusiasm and insightfulness to Mikhail's needs have allowed him to have an extremely positive swim experience.”

Ryan adds that Making Waves is essential to the social growth of children like Mikhail. “Often, it's very difficult for our children to foster friendships, given the barriers they face,” she explains. “It's far too common for them to be isolated with limited or no friends. Here, children can relate to one another and parents are able to network and form friendships as well.”

Theah Porritt, 6, has been diagnosed with autism and hyperlexia, which means she has above-average IQ and word-reading ability. She had severe speech delays and still struggles, especially with social interactions. Theah also has many gross-motor challenges, and sensory sensitivities particularly around certain noises. Touching wet or cold things also makes her highly uncomfortable.

Theah's parents discovered Making Waves Montreal by chance, while searching online. “We thought it would be a great way to help her be comfortable in the water, for safety reasons, and also a way for her to have more social opportunities with peers,” says her mother, Heather Porritt. “Plus, managing the financial



aspects of Theah's care is stressful, so we appreciate that the students offer this program at a nominal fee by volunteering their valuable time. The program is a blessing."

Porritt celebrates her daughter's improvements with pride. "Kicking in the pool [was] really tough for Theah at first, because she can't see her feet behind her, and often tries to look back, to know if she is doing it. Not being able to see her legs kicking makes the motor planning very difficult."

Theah's parents sing the praises of the program's devoted volunteers. "It's impressive how these students have been so dedicated in taking on such an endeavour," says Porritt, adding that Theah's two instructors have been "wonderfully patient and supportive. Like [with] every kid learning something new, you need to push their boundaries a bit at a pace that promotes learning without going too far. With a kid on the [autism] spectrum, that gets more complicated, because the sensory issues often have a big impact on the task at hand. Knowing how much to push without causing a sensory meltdown is not easy, especially for a volunteer instructor dealing with a special needs child in the water. It's a very delicate balance and we have been impressed at how the instructors have done."

Mastering that delicate balance

Because the instructors aren't trained to work specifically with exceptional children, Making Waves has a strong community support system in place in each city. "We recruit two or three very generous volunteers who come talk to our instructors each semester," explains Morantz.

At the Montreal chapter, for example, Tara Sloan, an occupational therapist,



PHOTO: MICHAEL GARFINKLE

Four-year-old Olivier Lachambre of Montreal loves being in the water, thanks to his dedicated instructor Aimee Huynh.

"We appreciate that the students offer this program at a nominal fee by volunteering their valuable time. Making Waves is a blessing."

primes the instructors on what to expect, notes Morantz. "She goes over the disabilities we most often encounter and advises on adaptive techniques for physical activity. Our returning instructors also provide in-pool guidance to our newer members."

Morantz and his team are developing an instructional video geared towards new instructors that incorporates lessons from the various professionals that have trained them. "They go over things like what to do when your child is misbehaving in the water or what to do when your child doesn't want to go into the water at all, a problem that we encounter fairly often," says Morantz. "It can be very intimidating for a child to come to an open space and see all this water and bright light and not

know what to do with a strange person that they've never met."

In these cases, says Morantz, instructors try to make children feel more comfortable by involving parents or giving them a familiar object or toy to focus on. If a child is scared of the water itself, instructors use sponges to slowly dribble water on a child's arms and legs while reassuring them. "Once they're comfortable getting wet, we give them the sponge and let them do the rest," says Morantz.

Major recognition

In 2009, Making Waves received Quebec's prestigious Forces AVENIR award in the category of mutual aid, peace, and justice. Created in 1999

Morantz' biggest dream is to go international, and to involve his instructors in global development initiatives.

to recognize, promote and honour students who have distinguished themselves by carrying out meaningful initiatives, it “encourages students to become involved in community service, humanitarian causes and respect for human rights or the establishment and promotion of a just society.”

The award spawned more momentum. Over the coming year, Morantz will launch new chapters in Niagara, Winnipeg, and St. John. He is also trying to organize chapters in Kingston, Guelph, British Columbia and Calgary.

“It’s a very time-consuming process that depends upon the willingness of students in other locations to give a large amount of time setting things up, [and] on pools to allow us to operate in their establishments,” explains Morantz.

Waves of the future

But Morantz’ biggest dream is to go international, and to involve his instructors in global development initiatives. “While the work we do in Canada is certainly important, there are regions of the world in which the plight of persons with disabilities is much more dire than in North America,” explains



PHOTO: JULIAN HABER

Matthew Morantz, founder and executive director of Making Waves Canada.

Morantz. “The reigning social regime in many countries is to ostracize, hide and forget persons with disabilities.”

This summer, a group of Making Waves alumni from across Canada will head to Lebanon and Mauritius to lay the groundwork for Making Waves’ international outreach activities. “Our goal is to create chapters at universities in foreign countries and see if we can influence the concept in other parts of the world,” says Morantz. “This way, rather than simply serving as instructors

for a summer and leaving afterwards, [our] impact will be sustainable, direct and important.”

The summer interns will mainly work with local stakeholders on advocacy, principles of inclusion, water safety information campaigns and the set-up of volunteer-based swimming instruction programs for exceptional children.

“The importance of these types of activities is all the more relevant in the context of Canada’s recent ratification of the United Nations Convention on the Rights of Persons with Disabilities,” says Morantz. “The success I achieved in expanding Making Waves across Canada was recently recognized by an Outstanding Commitment Award from the William J. Clinton Foundation, which has agreed to fund the first cycle of this program.”

Back at home, little Theah’s mom, Heather Porritt, notes that “Making Waves is a place where kids can feel respected and appreciated, where there is a caring group of students believing in their potential to be successful well beyond their challenges.”

Six years after becoming involved with Making Waves, Morantz continues to be inspired daily by the children he meets. “One 11-year-old with global developmental delay [recently] came up to us after his lesson, waving his hands. He was extremely excited, because he’d been able to swim four lengths by himself for the first time since he started two years ago. He was shouting, ‘It’s a miracle! I can swim!’ His parents had tears in their eyes. That’s a huge accomplishment for us. I get such enjoyment out of seeing all the kids having fun; it makes my time feel very well spent.” ■

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In

Focus

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

So Many Choices – So Overwhelming!

How to make the best decisions for your child



Many parents in my clinic tell me that they feel overwhelmed by the choices they have to make around their exceptional children, and worry they're not up to the challenge. In this issue we'll explore ways in which parents can learn to relax and feel good about the choices they make.

PHOTO: JULIAN HABER

In previous generations, when parents were told their child had a disorder or disability, they were lucky if there was treatment available. Otherwise, it was a matter of letting nature take its course. Although parents might have wished more could be done for their children, they had no choice but to make the best of it.

With each generation, more medical, therapeutic, and educational developments have provided more treatment options, resulting in an abundance of choices for many of today's parents. However, additional choices also mean increased pressure on parents to make the *right* choices, which in turn can add to their anxiety and guilt (which are quite normal reactions).

Even before their children are born, parents are often faced with difficult



Additional choices also mean increased pressure on parents to make the *right* choices, which in turn can add to their anxiety and guilt.

choices; sometimes these begin even before children are conceived. Many couples now know (with cold, scientific certainty) the odds that they will pass on a genetic disorder to their offspring. They can choose to have children biologically, through surrogacy, or adoption. They can request genetic testing during pregnancy or opt for IVF (in

vitro fertilization) with genetic testing pre-implantation. Individually, each choice demands much consideration. Collectively, they can be overwhelming.

For other parents, a special needs diagnosis comes later, out of the blue. But whether expected or a shock, learning that one's child will have

special needs is an emotional experience. Yet even while the news is sinking in, parents have to begin making decisions immediately. The need to make choices often continues for the rest of their child's life: Keep working or stay home? Which treatment or medications are best? What if a treatment is controversial or alternative? What about vaccines – should I give my child all, some, or none? Do I tell others if the disability is not visible? What do I tell the child? Start education early or keep him or her at home for a few years? Integration or special education? Academic studies or vocational training? Allow dating? Talk about sex? Remain at home in adulthood or transition to a group home? The choices can seem endless.

So how can parents benefit from so many options without being overwhelmed by them? Here are some helpful tips which will enable you to celebrate choices, rather than dread them:

Trust yourself. No one knows your situation or your child as well as you do – not even the doctor! As long as you're not in denial about your child's condition or abilities, you can probably trust your inner voice to guide you toward the right choices.

Trust others. You don't have to feel alone in making these decisions. But don't trust others blindly – you need to be able to assess who you *can* trust. So how do you do that?

In doctors, therapists, educators and other professionals, look for individuals who are open to *various* treatment options, rather than an exclusive therapy or program because it's the *only* one they believe in. There are almost always options. You want to seek guidance from someone who will be able to discuss all of your child's options with an open mind, someone who will actively listen to

What other exceptional parents have said about making choices:

"I once had to choose between a doctor of traditional medicine and a practitioner of an alternative therapy. The practitioner wanted to work closely with the doctor. The doctor refused, without explanation – it was just a knee-jerk reaction. For me, it wasn't a choice between treatments, but between the kind of person I could trust."

"When I can't decide what to do, I repeat my own version of The Serenity Prayer: God grant me the serenity to accept the things I cannot change, even though they may not have been my choice; the courage to choose to change the things I can; and the wisdom to make the best choices I can."

"Every family has its priorities. Some value education over everything else. But when I had to pick between a higher education and my daughter's mental health, it was a no-brainer. I'd rather she feel good about herself than have a piece of paper saying she lived up to other people's expectations."

your concerns, and then offer an informed opinion around why one or more choices may be best for you and your child in light of his or her particular situation.

The same goes for friends and family members. Again, you should seek out

individuals who are open-minded, who know your situation, and understand that what worked for them or for their hairdresser's cousin's little boy, might not work for you.

Baby steps. Don't take on too many decisions at one time. Identify one



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despite your best efforts, continuing to fight tooth and nail can be financially and emotionally draining. Instead, you might consider switching schools and devoting your energy to a more productive battle.

Cut yourself some slack. You have many realities to deal with, in addition to your child's condition. Other children, for instance, or financial issues, and/or your own skill sets (both strengths and weaknesses) may play important roles in your consideration. Don't feel guilty about your choices. You're not accountable to anyone but yourself – and especially not to people who "just don't get it."

Shades of grey. All choices have advantages and disadvantages; few are black and white. Several different paths can often lead to positive outcomes. When you come to a crossroads, don't stand there paralyzed with fear that if you make the wrong choice you'll be lost forever. Make the best informed choice you can, and go forward with confidence.

Above all, remember that if you've made a choice based on the best information you could obtain, from sources you trust, and with the best interests of your child at heart, then it was the best choice – whatever the outcome may be. ■

problem and focus primarily on that. Your confidence will grow with each choice you make.

Pick your battles. Recognize what you can and can't change. For example, if the school is resistant to providing what your child needs and is entitled to



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



Quack therapy and developmental disabilities

Protecting your child and your wallet

by JAMES COPLAN, MD, FAAP
Neurodevelopmental Pediatrics
of the Main Line, PC

Quackery has been with us longer than scientific medicine. Quackery is defined as medical self-promotion, beyond what the evidence shows. The term originates from the word *Quacksalver* – Medieval street vendors, who went around boasting (“quacking”) of the power of their salves. Quackery need not involve intentional fraud. Indeed, most quacks genuinely believe in the value of the products or services they provide.

Parents of a child with a developmental disability face the challenge of deciding which treatments to adopt – and, equally importantly, which treatments to *avoid* – in order to optimize their child’s chances for a full and productive future. We cannot cover all possible forms of quack therapy in these few pages. What we can do, however, is

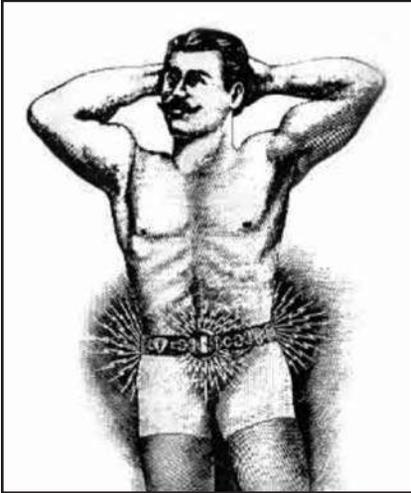
alert you to quackery’s telltale warning signs. This list is not perfect, but the symptoms of quackery have remained depressingly constant from generation to generation.

First, consider who, *other than the providers and consumers of a given therapy*, is promoting it. Providers are almost always biased; it is nearly impossible to remain objective when one’s livelihood is at stake. Likewise, parents who have committed large sums of time, energy, and money to obtain a given therapy for their child have an emotionally-based need to believe in the value of what they have done. This is called “reducing one’s cognitive dissonance” – we all do it, all the time. (Simply put, we all try to convince ourselves that what we are doing is good and proper). If no one other than the buyers and sellers of a particular therapy are speaking up on its behalf, then proceed with caution.

The specifics of the quack’s “pitch” also have remained dismally constant for the past 200 years. Once you develop an “ear” for them, you will be surprised at how blatantly they jump off the page.

All powerful, but completely safe. No treatment is completely safe, not even drinking a glass of water. Anyone who claims otherwise is guilty, at the very least, of gross self-deception.

Simple, yet mysterious. Quack cures are typically claimed to harness some essential force or element, to achieve their wondrous ends; magnetism, electricity, oxygen, and radioactivity have all been touted as “cures.” Oxygen was promoted as a cure-all by the Canadian physician, Hercules Sanche, during the late 19th and early 20th centuries. As horrifying as it sounds to us today, radium was a key ingredient in over-the-counter

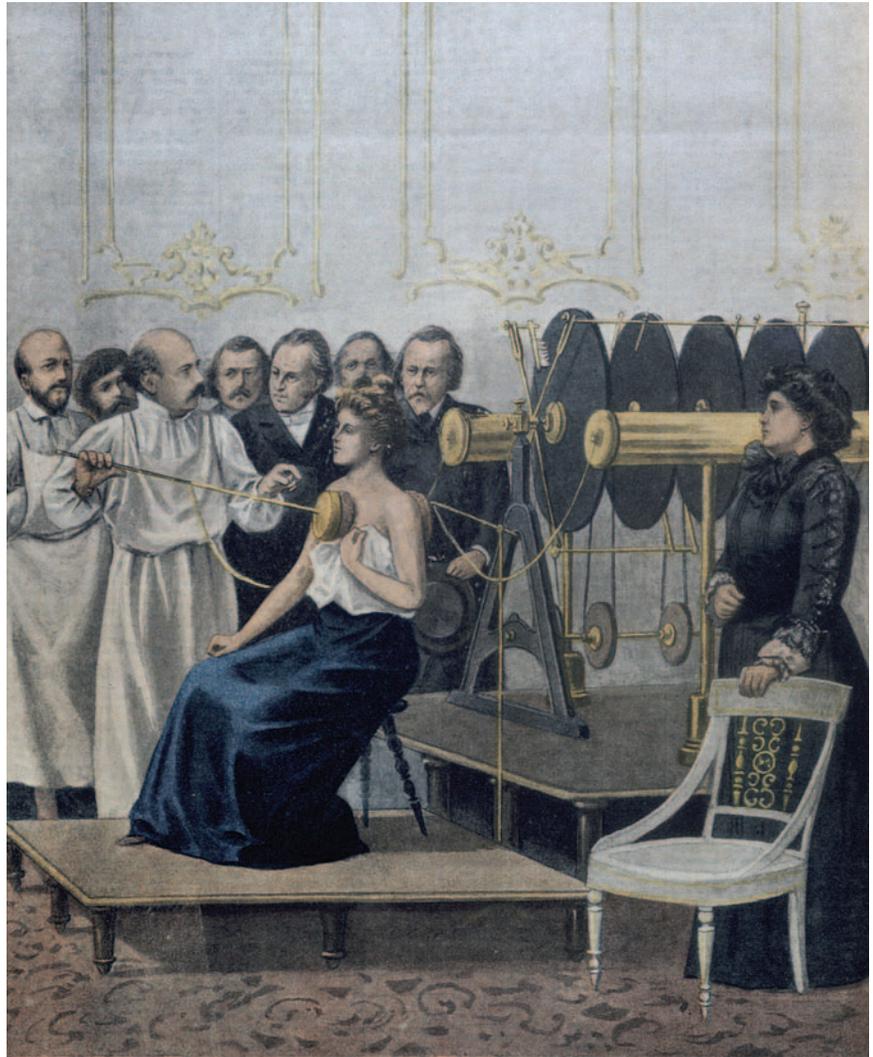


The Heidelberg Electric Belt (circa 1900) coincided with the introduction of AC current as a power source.

quack medicines, up through the 1930s. Even today, you can go onto e-Bay and find tins that once contained “Arium” – radioactive tablets sold as a cure-all. I’m not sure I would buy one, because they may still be “hot”.

3 Shadows legitimate science. In each generation, quacks adopt the trappings and verbiage of mainstream science and/or popular culture, to weave an emotionally satisfying narrative of disease causation and cure – minus all of the complexities and uncertainties that beset genuine science. The telegraph – an electromagnetic device – was invented in the 1840s. Magnetism as a “cure” was popular around the same time. When electricity emerged as a power source at the end of the 19th century, quack cures followed right along (*above*). Radioactivity as a “cure” enjoyed its heyday in the first quarter of the 20th century, at a time when luminaries such as Marie Curie were in the limelight for their work on elucidating the workings of radioactive decay.

4 Cures multiple disorders. Quack therapies often claim the ability to cure multiple diseases – typically, disorders that are not curable by



Doctor Francisque Crotte treating a tuberculosis patient with electricity (1901).



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conventional means. The aforementioned electric belt was claimed to remedy “NERVOUS DISEASES of all kinds ... weakness in men and women, personal exhaustion ... impotency, rheumatism, sciatica, lame back, railroad back, insomnia, melancholia, kidney disorder, Bright's disease, dyspepsia, disorders of the liver, female weakness, poor circulation, weak heart action and almost every known disease and weakness.” A popular therapy for autism advertised on the web today claims that it can help children with “heavy metal damage, autoimmune damage, intestinal inflammation, yeast, viral and bacterial infections, and cellular energy dysfunction.” Notice any similarities?

5 Supported mainly by testimonials. Intellectually, we know that coincidence does not establish cause-and-effect; the percentage of people carrying umbrellas goes up just before a shower, but we do not believe that

umbrellas cause rain! Parents and therapists are tempted, however, to attribute improvement in a child's picture to whatever therapy the child has undergone, even though the perceived improvement may represent placebo effect, or neurologic maturation (*see right*). Even if the improvement is real and reflects treatment effect, the people speaking on behalf of a given therapy may not be representative of the entire sample of individuals who have tried it. This is why treatments should be validated by randomized controlled trials. Heartfelt testimonials may be a useful starting point for research, but they do not constitute evidence in and of themselves. This writer is old enough to remember JFK's inaugural address: “Sincerity is always subject to proof.”

The same skepticism of testimonial “evidence” of treatment efficacy applies when evaluating purported causes of disability: For every parent who is

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“Tincture of Time” used to be a favorite medical prescription. In this case, one might ask “Wouldn't a child learn to walk and talk in 12 months anyway, regardless of Dr. Dan's ministrations?” The answer, of course, is yes. But many popular therapies are based on evidence no stronger than this. (© James Coplan, 2010, used with permission)

prepared to swear that their child became autistic within 48 hours of



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getting vaccinated, there are hundreds, probably thousands, who make no such claim (or who report autistic regression at some other point in the child's life). The "evidence" for shots causing autism, therefore, is slim indeed. Likewise, there is no evidence at this time that gluten in the diet, or yeast in the gut, cause autism. Evidence that withholding shots, or eliminating gluten from the diet or yeast from the gut do anything to improve autism, is non-existent.



Glorification of Victimhood.

Quacks often depict themselves as the "noble underdog," persecuted by mainstream medical science. And the more evidence that accumulates to discredit the quack, the more ardently the quack's admirers defend him (or her). In its most extreme form, quacks depict the scientific establishment as

actually causing the problems for which the quack claims to have a cure. "It is pardonable in you to want to know these formulas, for they are good. But you must not ask us to reveal these valuable secrets, *to do what you would not do yourselves.*" So said W.A. Talbot, owner of Piso's Consumption Cure, and president of the Proprietary Medicine Association, speaking out against the American Medical Association's support of pure food and drug legislation, in 1905. The idea that doctors have caused an autism epidemic by unleashing immunizations on hapless children plays directly to these sentiments.

Look for these elements in whatever therapy you are contemplating for your child. If it looks like a duck, walks like a duck, and quacks like a duck, it's probably a duck – or quackery. ■

ADDITIONAL READING

Coplan, J. **Making sense of autistic spectrum disorders: Create the brightest future for your child with the best treatment options.**

Bantam-Dell, 2010. Chapter 13: *Sense and Nonsense in the treatment of autistic spectrum disorders.*

More on Dr. Sanche: http://objectwiki.sciencemuseum.org.uk/wiki/Oxydodor_No.2

Quackwatch:

www.quackwatch.com

The author's favorite website dealing with quack medicine of all types.

For a reminder of how the themes of medical quackery never change, read "The Great American Fraud," originally published in Collier's Magazine (1905-1906). The first installment is available online at wikipedia: <http://en.wikipedia.org/wiki/Quackery>

For a chilling account of radium as a quack cure, read: Macklis, R., "The Great Radium Scandal," Scientific American. 1993. p. 94-99

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With over 23 million web pages, feds have work cut out for them



The federal government has 15 months to make all of its websites accessible to users with visual impairments, after a Toronto woman launched a constitutional challenge and won. Donna Jodhan, who has been blind since birth, sued the federal government last fall after years of trying unsuccessfully to apply for employment on its job bank site. Despite having earned an MBA from McGill, technical certifications from Microsoft and Novell, and winning four accessibility design awards from IBM, Jodhan claimed that she had to rely on others' assistance to navigate the website, since it was inaccessible to her as one who is blind. Arguing that her

equality of rights under The Canadian Charter of Rights and Freedoms had been violated, Jodhan cited The American White House website, which features audio clips and captions, as an example of accommodation. Despite defence arguments that Jodhan could have accessed the job postings via telephone, mail, or in person, Justice Richard Mosley of the Federal Court recently ruled that the website discriminated not only against Jodhan, but all people with visual impairment.

Teen blogger with autism given prime forum to make her voice heard

Four years after breaking her silence and revealing her ability to communicate, a non-verbal teen has been given a forum to blog about her condition on the CTV website. Fifteen-year-old Torontonian Carly Fleischmann has autism and apraxia. While her prognosis was initially grim, her parents persevered and enrolled Carly in an Intensive Behavioural Intervention program, a form of Applied Behavioural Analysis, considered by many experts to be the most effective evidence-based therapy to date for children with autism, according to Autism Society Canada. At age 11, Carly shocked everyone around her when she began to express herself by typing on a computer. Beginning with simple words, Carly proceeded to construct full sentences, and in the process, exposed her intelligence and capacity to feel emotions.

In addition to blogging for CTV, Carly – who types at a painstakingly slow pace with a single finger – has her own website, Facebook and Twitter followings. CTV first featured Carly's story in 2007. She has also been on CNN's Larry King Live, and ABC News. The teen plans to use her blog to shed light on the "myths and misperceptions about autism" from an insider's perspective.



Passing airport security a nightmare for people who wear prosthetics

At a time when many North Americans are up in arms over airport security screening procedures, the Amputee Coalition of America (ACA) is drawing attention to the significant discomfort experienced by air travellers who wear prosthetics. In a 2010 survey conducted by the ACA on 7300 Americans with amputations, respondents reported undergoing undignified, embarrassing, "unfair" and even "abusive" security checks by Transportation Security Administration (TSA) officials during routine screenings, *Popular Mechanics* magazine reports. ACA board member Dr. Jeffrey Cain, who has a double below-the-knee amputation, noted that while the TSA's vigilance around prosthetics is justified, it should strive to implement standardized screening methods throughout the U.S. The TSA and ACA have discussed the possibility of pre-approving travellers who wear prosthetics and equipping them with cards that would enable them to pass through security more quickly. According to *Popular Mechanics*, air travellers with below-the-knee amputations must often have their prosthetics x-rayed more than 10 times.



Proposed bill aims to keep offenders on a tight leash

Saskatchewan residents who depend on service dogs may be able to get compensation in cases where their animals are victimized by people or other dogs, if the New Democratic Party gets its way. As reported in *The Regina Leader-Post*, a recently proposed private member's bill in the Saskatchewan legislature suggests that people who rely on service animals should be entitled to claim damages from offenders for any costs associated with their animals' rehabilitation, obedience training, or even replacement. While animals are already protected under Section 446 of the Criminal Code, Saskatoon Centre NDP MLA David Forbes, who introduced the bill, said the law doesn't recognize the "unique cases" of service animal owners, whose pets perform an integral role in their daily lives, and therefore need to be able to return to their "jobs" as quickly as possible.

ASL users will soon be able to chat via mobile videoconference

American Sign Language users in the U.S. will soon have the ability to communicate face to face on their cell phones, thanks to University of Washington (UW) engineers. While videoconference technology is already available on phones equipped with front-facing cameras, their image quality cannot capture ASL signs with precision. Mobile videoconferencing also uses up significant bandwidth, which often translates into expensive phone bills for users. Moreover, some videoconference apps, like the iPhone 4's FaceTime, are limited to those with WiFi access.



UW engineers are developing MobileASL, a device that uses 10 times less bandwidth than iPhone 4 during videoconferencing, and delivers superior image quality around the areas of the hands and face so that viewers can see ASL signs clearly. It's also equipped with motion detectors that sense when someone is signing so that phone batteries may be preserved during inactive periods. MobileASL project leader Eve Riskin, a UW electrical engineering professor, said the goal is to "deliver affordable, reliable ASL" and give all people equal access to videoconferencing – a medium that enables speakers to make eye contact, view each other's emotions, and have long dialogues rather than brief text exchanges.

In the Best Interest of the Exceptional Child

Determining living arrangements in the event of separation or divorce

By Dr. ABE WORENKLEIN

Parents of exceptional children require skills that generally surpass those needed to adequately parent children without disabilities. These may include increased patience, attention, consistency, predictability, time and active involvement. Exceptional parents deserve credit for their efforts and resolve. Yet having a child with special needs often creates a great deal of tension between parents, particularly when the needs demand significant time and attention and when the seriousness of the challenges leads to tremendous frustration. Often, parents do not see eye to eye in terms of the “cause” of the condition affecting their child, the best methods for intervention, which professionals to seek out, and even the coping style that each employs to deal with their child’s reality. Recognizing that increased stress on the family often accompanies having an exceptional child, it is no wonder that the rate of separation and divorce escalates when a child has significant special needs around which conflict develops.

Having conducted more than 700 custody evaluations over the past 35 years,



I have had to accept the unfortunate reality that parents at times become so entrenched in their points of view, that they cannot see the forest for the trees. Rather, each tends to view litigation as an attempt by the other to

continue to exert control through their child. This may be the case. But who is the loser? The child. Both parents and professionals need to remember that we are there to address the child’s needs, *not* the parents’ rights.

Potential disputes in high-conflict cases

In cases of high conflict, parents frequently dispute not only the "causes" of their child's difficulties, but whether the child, in fact, has a problem, whether he or she even needs intervention, and if so, of what nature. When parents are in the midst of a custody litigation, disagreements around medication, public versus private school, or specialized school are often blown out of proportion. Allegations of neglect are sometimes raised by one parent against the other. The situation is often greatly



In situations where there is an exceptional child, it is even *more* imperative that parents put their feelings aside.

aggravated by the polarization of many of the involved professionals, who often arrive on the scene as a result of one parent's shopping around for a divergent opinion due to a deep distrust of the other. This distrust may also manifest in the child being medicated in one home while receiving

nutritional or homeopathic interventions in the other home. Similarly, behavioural accommodations may be implemented in one home but refused or even negated in the other. Extra-curricular activities implemented by one parent to help develop a child's self-esteem in light of academic and

social difficulties, for example, may be undermined or neglected in the other home. In essence, the child's need for success is redefined and adapted to the parent's best interest and not the child's.

In the event of a separation or divorce, parents' feelings about each other often cloud their judgment and ability to advocate for their child. In situations where there is an exceptional child, it is even *more* imperative that parents put their feelings aside so that the living arrangements "cut the suit to fit the child" and not "the child to fit the suit."

Considerations when determining living arrangements

When I began conducting custody evaluations in 1977, it was common to refrain from recommending overnight access for any child – exceptional or not – much before age five. Today, we recognize the benefits of granting overnights to children at much younger ages in situations where both parents are actively involved in the child's daily care and the child is equally comfortable with both.

Although it is well known that the ultimate criterion in deciding a child's

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living arrangements is predicated on the child's best interests, unfortunately the needs of exceptional children are often given inadequate weight. While volumes have been written on the subject of custody evaluations, little has been devoted to the special considerations that ought to be taken when determining an exceptional child's living arrangements. A child's specific special needs may dictate living arrangements that deviate from what might be recommended in situations involving "typical" children.

Among evaluators' considerations when recommending living arrangements are the exceptional child's challenges and needs around diet, activity level, medication, consistency of routine, etc. For example, inconsistent behavioural-management techniques can be confusing for any child, but extremely confusing for a child who has limitations in different areas of functioning, such as intelligence, language-development,

Children with behavioural challenges, for example, require parents who are patient and who provide a predictable routine with consistent expectations and consequences. Children with a pervasive developmental disorder or with Attention Deficit Hyperactivity Disorder generally require consistency and predictability in their routines as well.



more frequently around their child's special issues. Parents must also be able to prioritize their child's needs and coordinate their parenting so that their child can feel secure and understood despite the ongoing conflict between them. Custody evaluators also consider that parents who may be experiencing difficulty accepting the termination of a relationship may also lack the emotional resources to provide for the exceptional child.

Professionals who are mandated to assist the court and to recommend a parenting schedule that best meets the needs of exceptional children must have training and experience as well as a great sensitivity to the challenges faced by such children and their parents. Using a cookbook method which only considers the child's age and the typical issues of their developmental stage is simply not sufficient in addressing the best interests of children with special needs.

Alternating between two homes with totally different parenting styles may promote more destabilization and insecurity.

memory, attention or organization. Moreover, some exceptional children have great difficulty adjusting to changes in their environment and insist on things remaining the same socially and environmentally, while others, because of communication challenges, may have difficulty comprehending what the changes are and why they are necessary.

Although joint custody may be viewed as beneficial to the child provided that neither parent demonstrates problematic emotional/behavioural traits, having a child with special needs alternate between two parents with totally different parenting styles may promote more destabilization and insecurity.

Because children who have significant intellectual /behavioural /emotional challenges often are at a lower developmental age than chronological age, custody arrangements should be geared to the child's developmental age and follow-up evaluations must be conducted as the child's development progresses. While this is necessary with all children, it is particularly vital with a child who is receiving interventions to narrow the gap between his or her functional level and actual potential.

Although effective communication between parents in any divorce situation is critical, it is even more vital in the case of exceptional parents since they must often communicate even

Clearly, the yardstick needed to make recommendations regarding the living arrangements of an exceptional child must differ from that used with a child who does not show a significant problem in his or her development. Parents and professionals must advocate for the child to ensure that the "Best Interests" criterion fully considers a child's special needs and the ability of the parents to meet those needs as a priority. ■

Dr. Abe Worenklein is a clinical/forensic psychologist in private practice, a professor at Dawson College and a lecturer at Concordia University in Montreal. Dr. Worenklein is also a board member of Miriam Home and Services and sits on the editorial boards of the American Journal of Family Therapy and Exceptional Family magazine.



Ask the Expert

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

Is it Fair to let my Daughter Have **Unrealistic Dreams?**

Q A couple of months ago, my husband and I married off our third of four daughters. Our youngest child, 21-year-old Kate, has Down syndrome and lives at home, although our intent is to transition her to a group home by the time she turns 30.

When our two oldest girls were married, Kate was a child; her biggest preoccupations surrounded her roles as flower girl – roles that earned her attention, fancy new dresses and the chance to be done up from head to toe. Now a young woman, her sister's recent wedding has ignited Kate's interest in relationships, dating and marriage. Kate works alongside a young exceptional man in a sheltered workshop, and while she refers to him as her boyfriend, she's really unclear about the concept of a significant other.

Since we began the wedding preparations months ago, Kate relentlessly asks: "When am I going to get married?" or simply begins sentences with, "When I get married..." (i.e., I will move to Ottawa). Her statements are easier to handle as I'm able to acknowledge them by shirking the marriage reference (I'll reply, for example, "Ottawa's a nice place to live"). But I dread when Kate asks me the question, head-on. I don't have the heart to tell her the truth – that she will likely never get married. So instead, I just say, "One day" or, "When the time is right", and immediately change the subject. I realize I can't keep putting my daughter off forever, I just don't know how to break the news to her gently, without shattering her dreams. How can I tell her that the time may never be right; that "one day" may never come?



PHOTO: LAWRENCE CLEMEN

A I understand your dilemma about what feels like a false endorsement of your daughter's wish to get married. Based on your belief that because Kate has Down syndrome (DS) such a wish is unlikely to be fulfilled, you wonder whether it would be wiser to be truthful with her about this prospect.

Although your concern stems from your desire to spare Kate from future hurt and disappointment, I commend you for employing your best instincts to protect first and foremost her right to give expression to her hopes and dreams. You have not attempted to thwart her fantasies any more than you would have when your other daughters expressed similar interests. Instead, you have provided appropriate validation by responding sensitively to her comments and questions about marriage.

As you see, I am distinguishing the idea that dreams for the future have a place even if we do not know for certain whether or not they will come to fruition. Noted psychoanalyst, Salman Akhtar, confirms this in his observation that all human beings function by projecting their hopes



Adults with DS share the same emotional and sexual desires as other adults. They are not permanent children.

and wishes into what he calls “someday fantasies”.¹ And Kate is no different from any of us.

The fact that Kate, who is 21, is dreaming about having a romantic relationship and getting married confirms what we now know about people who have DS – that although they may reach developmental milestones at a slower rate than average, and function mostly at a level of mild to moderate mental retardation, adults with DS share the same emotional and sexual desires as other adults. They are not permanent children.

Based on this understanding, predictably, Kate’s exposure to her sister’s wedding plans has brought her to voice feelings which would have already taken root inside of her. Along with her references to a “boyfriend” at work, this signals a turning point in Kate’s development. You must now consider your response not only to the childlike part of her that you have been protecting until now, but to the mature, adult part as well, which is generating needs and impulses beyond your control – a challenge which goes beyond the issue of whether it is alright to verbally avow Kate’s wishes.

Hopefully, keeping in mind your observations about Kate’s naivety regarding the meaning of boyfriend-girlfriend relationships, you have already put into place the teaching of those life skills which involve the creation of appropriate boundaries, practice in making choices, as well as sex education, which are so necessary in helping her to negotiate this new stage in her experience.

But, there is another aspect which bears consideration and that is, to what extent Kate’s adult desires for

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¹ (1996) Journal of the American Psychoanalytic Association, 44:723-753.

marriage have the right to be met in reality. The underlying assumption in your letter is that the odds of Kate herself getting married are too negligible to warrant actual support for her wishes.

Indeed, several years ago this would have been the case, especially since the adult lifespan of people with DS was relatively short. Yet, today, with people who have DS living to 60 and beyond, what seemed like such a far-fetched

serious considerations, both practical and emotional, on the part of the couple and the extended family which must be addressed if the marriage is to be sustained.

Couples who marry generally need to reside with, or be in close proximity to, other family members who can be attentive to them and oversee their functioning. They



Monica and David star in HBO's award-winning documentary.

Today, with people who have DS living to 60 and beyond, what seemed like such a far-fetched idea is gaining acceptability.

idea is gaining acceptability, resulting in growing evidence of success stories of couples who marry in which both partners are affected by DS or in which one partner has DS and the other, another form of disability.

A recent award-winning documentary entitled *Monica and David* (produced by HBO Documentary Films) realistically depicts such a marriage in terms of the love and joy which radiate between the couple, as well as the challenges involved. It is by no means a simple prospect. There are many

will almost inevitably require financial support since in Canada, as in other places, benefits for those with special needs are terminated when they marry, on the presumption that marriage is equated with self-sufficiency. The question of reproduction must be addressed as does the capacity for childrearing, which may be further complicated by the increased genetic possibility of having a child with DS.

Clearly, marriage should not be considered as an expected outcome for everybody who has DS. And I cannot

presume to know whether it would be a suitable option in Kate's case. I do know that it constitutes a powerful wish on her part which I hope will be given due consideration for her sake. There is new understanding about the potential for people with DS to live longer, richer and more meaningful lives. And society is gradually shifting to accommodate adults with DS choosing to marry. Not very long ago, these were wishes which were considered unlikely to come true. ■

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

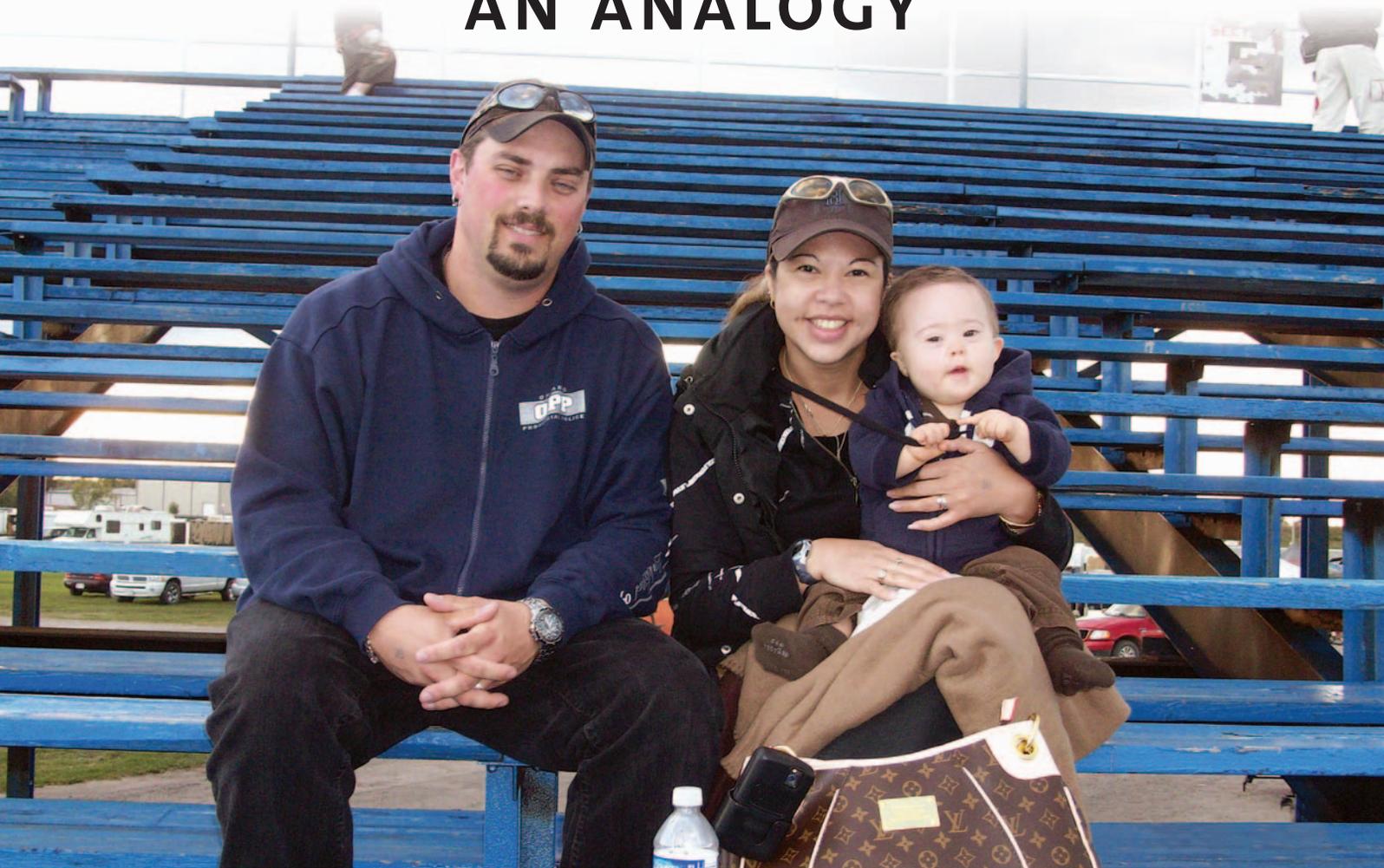
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Welcome to our House

AN ANALOGY



The McWade family: John, Sandi and their son Hunter, at 12 months.

by SANDI GRAHAM-McWADE

After many months of dreaming, you finally decide it's time. You are going to build the perfect house of your dreams. You have saved and saved, and now it's time to put your plan into action. You find a wonderful, perfect piece of land in the city. It's exactly what you are looking for. You envision the all-brick house sitting on luscious green grass, surrounded by a white picket fence. Inside is a marble foyer leading into a family room with beautiful oak hardwood floors. Granite lines the kitchen countertops and there is an island sink in the middle. Upstairs, there are four perfect bedrooms and the master bedroom has an ensuite bathroom and an enormous walk-in closet, of course. It's truly a dream come true, and it's only a matter of time. You purchase the land and think to yourself, *in nine short months, I will have it all.*

But suddenly your agent calls to tell you that the land is not properly zoned, and the city has not approved it for building your perfect home. Instead, the city has given you land in the country, where an old country home sits. You are absolutely devastated; your dreams vanish right before your eyes. But you know you can't back out now – you need a place to live, and despite it not being what you wanted, you know that somehow you will manage.

You know that everyone else has a nice city home, and that was what you had planned, but you have to come to terms with the fact that you must learn to live in the country.

You tell everyone what has happened, and everyone is disappointed; some even offering their condolences. You know that everyone else has a nice city home, and that was what you had

planned, but you have to come to terms with the fact that you must learn to live in the country.

You go to see the property every month until closing and something funny happens: you start to fall in love with the place. The air is fresh, it's peaceful and serene. There's a pond on the land, and the house, though not a new all-brick home, is quaint, and has lots of hidden potential. You

soon realize it's not an awful place, it's just a different place. It's slower-paced than the city, less noisy and flamboyant, but it's beautiful none the less. And in the process, you soon realize you may even get to meet some new and wonderful neighbours.

It's closing day and you suddenly find yourself full of anticipation, but you are still a little worried. After all, it isn't what you had originally hoped for, and the house may need some repairs. But you are determined to accept it, and tackle everything one step at a time. You open the front door, and suddenly you are thrilled with what you see. The house is lovely, and has lots of character. All of

the rooms are smaller but they are decorated with beautiful attention and detail. The kitchen has marble countertops instead of granite, and the bathroom has a soaker tub instead of a Jacuzzi. There isn't a walk-in closet in sight, but the rooms all come with an indescribable view. Somehow, you just know that it was always meant to be and that this is now home.

This is my analogy of what it will be like for people who discover that they will be caring for a baby with Down syndrome. For us, it is not a terrible place to be. It is a journey full of surprises, milestones and discovery, as it would be with any other child. And as the story suggests, sometimes it's only a matter of point of view. Surprisingly, once you have been there, you don't want to be anywhere else. The journey, like all others, doesn't come without some bumps in the road; but once you find your way, it's all about the place you've discovered, in most cases – quite by random chance. ■

Sandi Graham-McWade is a veteran police officer, an author and an advocate for people with DS. Sandi has created several support groups including a local YMCA parent/child playgroup for kids with special needs. Read more about her journey at www.welcometoourhouse-myjournal.blogspot.com.

Have something to say about an article you've read in Exceptional Family? We welcome your feedback! Drop us a line at feedback@exceptionalfamily.ca



Sandi and 17-month-old Hunter

Expecting Adam

By Martha Beck
Berkley Books, 1999
328 pages, \$18.00



Were it not for her two Harvard degrees, award-winning writing style, and the fact that author Martha Beck makes rational arguments throughout her memoir *Expecting Adam*, one might easily question her cognitive soundness and sophistication as she recalls numerous paranormal experiences that touched her while pregnant with her son, who was diagnosed with Down syndrome in utero. From visions and voices, to hands that shepherd her to safety during near-death incidents, Beck is the first to acknowledge the eccentricity of her claims that she felt a supernatural presence in the nine months preceding Adam's birth. And yet, as Beck relays, her husband (and fellow Harvard graduate), John, often felt those very same spirits – or puppeteers, as she calls them – lending credence to the notion that surely they couldn't both have been mad.

In a gripping story that spans 32 chapters, Beck recounts the couple's challenge to cope with their unborn child's diagnosis, and their decision to keep him amidst

People pay me good money to pass along to them what Adam teaches me for free. Luckily, I'm pretty sure he will never demand a percentage of the take. It scares me to think how much I owe him.

- *Expecting Adam*

others' incredulity. To add to their stress, both simultaneously pursue careers while raising their toddler, Katie, and John attempts to complete his doctorate degree which necessitates frequent commutes to Asia. The author, meanwhile, fights unrelenting nausea and dehydration that land her in the hospital on numerous occasions.

Consistently poignant and frequently laugh-out-loud funny, Beck leaves readers with a clear understanding of her views on such topics as the Harvard community ("...I don't know if I ever met anyone at Harvard who found it pleasantall these people scurry anxiously from one achievement to another, casting wary glances over their shoulders, never quite sure that they've managed to throw failure off their scent"), her in-laws ("They

can discuss the maintenance of the flowers in their yard or the recipe for meat loaf for thirty minutes at a stretch, never once letting their attention lag"), or the institutionalization of people with disabilities ("....putting a person with Down's into an institution is like forcing an otter to live in a Pringle's can).

Like aged cheddar cheese, Beck's words are often sharp. She frequently refers to Adam as a "retarded" child, a reference she neither apologizes for, nor dances around. At over 300 pages, certain parts of *Expecting Adam* could have been condensed; nevertheless, the book's timeless appeal and compelling content make it an instant classic, unequivocally deserving of its status as a national bestseller. ■

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

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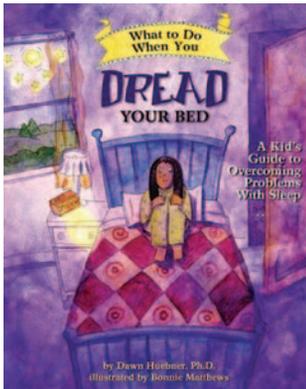
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What to Do When You Dread Your Bed: A Kid's Guide to Overcoming Problems with Sleep

By Dawn Huebner, Ph.D.
Illustrated by Bonnie Matthews
Magination Press, 2008
96 pages, \$18.50



by LAUREN SILVER

Just when you've resigned yourself to the fact that bedtime in your home will always be a drawn-out, patience-testing process, along comes *What to Do When You Dread Your Bed*, a hopeful book that targets some of kids' greatest bedtime-related concerns. From noises and monsters, restlessness and swirling minds, to over-stimulation and fears of being alone, psychologist Dr. Dawn Huebner employs cognitive-behavioural techniques to treat children's sleep issues and help them to develop healthy new bedtime habits.

Geared for kids ages 6 to 12, the guide's 12 chapters each begin with a magic trick that is cleverly tied in with a unique message. By encouraging readers to perform the tricks, Huebner empowers them with the confidence to master skills that may also be applied when establishing and maintaining their own bedtime routines.

The multiple sources of children's sleep troubles are identified, and

Wouldn't it be great if you could climb into bed, snuggle under your covers, and fall asleep without any fuss or fear? Without listening for noises or thinking about bad guys? Without an extra drink, or an extra hug, or an extra trip to the bathroom?

- *What to Do When You Dread Your Bed*

the beginning of the book educates readers about the ideal amount of sleep they should be getting. Subsequent chapters delineate numerous healthy bedtime habits that may be practiced in order to facilitate proper sleep routines, such as how to properly prepare for bed beginning one hour before a child's target bedtime. Huebner encourages children to create their own bedtime routines and addresses issues that may prevent them from sleeping soundly through the night. The author also advises readers on how to overcome fears of the dark, monsters, and nightmares. Finally, she encourages them to separate from their parents around bedtime in order to help diminish any urges to visit Mom or Dad during the night.

Printed in large type, *What to Do When You Dread Your Bed* contains illustrations and activities that encourage reader participation. One task asks children to describe their dreams, while another asks them to draw themselves in bed.

At 96 pages, the book may present a challenge for younger readers. Moreover, the magic tricks introduced in each chapter also seem forced and unnecessary at times. One of the more elaborate card tricks is rather time consuming, which may also frustrate some readers. However, for families with issues around sleeping habits – and parents tired of getting “just one more” glass of water – Huebner's suggestions will come as a welcome tool for change. ■



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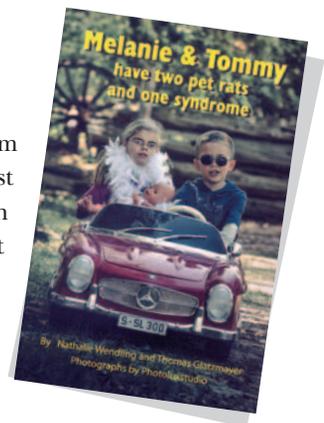
Melanie's Book

John Glatzmayer and Nathalie Wendling with Melanie, 10, Tommy, 8, and Smokey, one of the family's three pet rats.

Family finds novel way to raise awareness about daughter's syndrome and celebrate her victories

by WENDY HELFENBAUM

Three years ago, eight-year-old Tommy Glatzmayer came home from kindergarten, announcing he was going to write a book. Unlike most young budding authors, however, Tommy wasn't only interested in telling stories about superheroes or aliens. He wanted to write about his older sister Melanie, who has a rare congenital condition called Cornelia de Lange syndrome (CdLS), a genetic disorder that affects about 100 Canadians and often leads to severe developmental and physical delays.



Tired of hearing his friends make fun of his sister, Tommy and his mother Nathalie Wendling self-published *Tommy and Melanie have two pet rats and one syndrome*, in August 2010. The 48-page book features dozens of photographs of brother and sister experiencing adventures, and co-stars the family's pet rats Cinderella, Ninja and Smokey. A French version will be released this summer.

"Tommy wanted to make it funny enough to entertain his friends," explains Wendling, who lives with her family in Manotick, Ontario. "I was in charge of making it informative and educational so it could be used to raise awareness about CdLS."

Because CdLS is rare, few doctors have seen cases of it, so a timely diagnosis is rare as well, explains Wendling. Researchers believe that 1 in 10,000 people has CdLS, but many CdLS patients are misdiagnosed, or suffer horribly for years before a proper diagnosis is made. Wendling should know; her daughter was one of them.

An agonizing start

One week after baby Melanie was born in April 2000, Wendling and her husband John Glatzmayer knew something was wrong. Melanie seemed to have an overload of mucus and saliva, and was choking many times a day.

“I slept with my hand under her head,” recalls Wendling. “Every half-hour, she would choke until I propped her up in a sitting position. Over the next 10 days, the crying episodes reached 36 hours straight. Then she would vomit violently for hours, and the cycle would start over again.”

The exhausted parents tried different types of milk, pacifiers, nipples, and sleeping positions. But nothing worked.

“I was just a disaster; the first chance I had to sleep more than two hours was that July,” recalls Wendling.

After enduring nine weeks of endless tests, including lumbar punctures, x-rays, ultrasounds and barium tests, doctors told Melanie’s parents they could not find the source of the pain. The family was sent home.

Over the next six weeks, Melanie cried day and night. “It was unbelievable and unbearable,” says Wendling. “My husband and I had to be strong. Sometimes, we wouldn’t speak for three weeks at a time. We had to preserve our energy for hospital trips, high fevers and sleepless nights.”



At four months old, Melanie weighed just eight pounds. She had figured out that it was painful to eat and drink, so she refused both food and water.

“Melanie gave up. We thought she was going to die,” recalls Wendling.

Further tests and surgery to put in a feeding tube revealed that Melanie’s

Fast facts

about Cornelia de Lange Syndrome (CdLS)

CdLS is named after Dutch pediatrician Dr. Cornelia de Lange, who first described the syndrome in 1933.

CdLS occurs in about 1 in every 10,000 live births.

The gene on chromosome 5 that causes CdLS when it mutates was identified in 2004. Common physical characteristics include low birth weight, slow growth, small stature, and small head size. As with other syndromes, individuals with CdLS have similar facial features. Typical facial features include thin, joined eyebrows, long eyelashes, short upturned nose and thin, down-turned lips.

Other characteristics include excessive body hair, small hands and feet, partial joining of the second and third toes, incurved fifth fingers, gastroesophageal reflux, seizures, heart defects, cleft palate, bowel abnormalities, feeding problems, developmental delays and limb differences (including missing limbs).

Cognitive challenges include absent or delayed speech, hearing abnormalities and vision problems. Sixty to 70 percent of individuals display some degree of autism spectrum disorder. Patients may exhibit such behaviours as persistent scratching, aggression or self-injury.

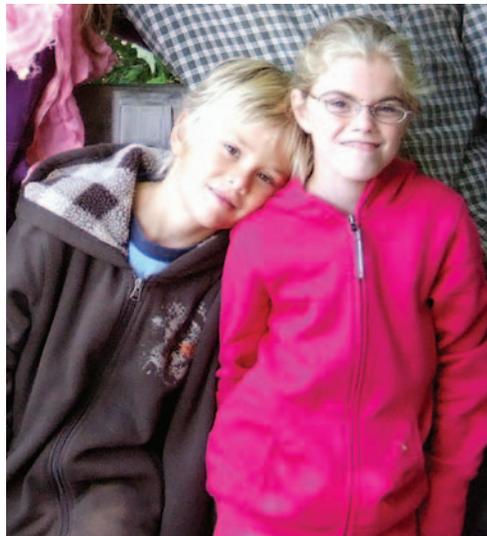
For more information about CDLS, visit www.cdlsCanada.ca

stomach was the size of a walnut, and the opening at the top was much too large, which meant nothing could be digested.

At the age of three, after being seen at four different hospitals in three cities, Melanie was finally diagnosed with CdLS in Toronto. “The doctor had seen another CdLS case, so it took her about five seconds [to diagnose her],” says Wendling.

By age seven, Melanie had undergone 10 more surgeries and continued to have serious eating disorders. She’d also endured years of chronic ear and sinus infections, double pneumonias, and recurring stomach viruses. Her chronic pain worsened her behavioural

to me, we were driving home from the hospital. She’d just been fitted with her hearing aids. I said, ‘Melanie, are you thirsty?’ and she answered, ‘No.’ Just like that. I had to stop the car, and I just started to cry.”



“The first time she spoke to me, I had to stop the car, and I just started to cry.”

issues. “Over the years, she’d learned that crying does not solve problems,” says Wendling, describing how Melanie tried to communicate her pain by grabbing her mother’s hair and pulling it as hard as she could. “The very worst thing is seeing your child in pain. For it to go on for years and years and years was just horrible.”

A light at the end of a dark tunnel

That same year, Melanie was fitted with hearing aids and glasses (many CdLS patients have hearing and vision impairments).

“Suddenly, every day was a little miracle,” says Wendling. “The first time she spoke

By age eight, Melanie’s condition began to improve. She was pain free for the first time in her life. That’s when brother Tommy’s book was born.

“Tommy is amazing. When he knows that we’re having a bad day with Melanie, he’ll just do anything to make the day better,” notes Wendling. “He never gives up. He has planets hanging from his ceiling, and he’ll bring her in and sit her down, and start teaching her about planets for an hour. And then the next day, he’ll do it all over again. With Tommy’s help, Melanie’s vocabulary increased from 20 to 500 words.”

As Melanie’s balance improved, “she became more coordinated, more social, more verbal, more confident, better

rested, more flexible, and her appetite improved,” notes Wendling. “Finally, she was going to school full time, attending birthday parties, skating, swimming, riding the school bus, eating lunch with her friends and hugging her brother.”

A full and happy life, with hope for the future

While Melanie still has up to 80 medical appointments a year and many developmental delays (she is not toilet-trained, cannot recite her alphabet or express pain), her life is a happy one.

Wendling hopes that sharing her family’s journey through the book and website will provide support to other families touched by CdLS. “My message is to give them hope, strength and the courage to keep going,” she says.

The family has participated in several book signings and readings in schools and seniors’ residences. Montreal’s Miriam Foundation, which is dedicated to improving the lives of people with intellectual disabilities, purchased 2,200 books to distribute across Canada. Feedback from parents, teachers and the public has been terrific, reports Wendling. The book’s last few pages feature questions and answers for children, parents and doctors. There’s even a section on how to take care of pet rats.

Wendling launched a video about CdLS in 2005 to distribute to doctors, and posted it on her website, www.2petrats.com. The book can be ordered online, and through many retailers listed there.

And Tommy? He’s most happy that no one makes fun of his “beautiful” sister anymore. The family’s pet rats continue to be therapeutic pals for Melanie, while also enjoying their newfound celebrity. ■

Exceptional Family Readers

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My Impaired Vision



Lucy Long at age 3.

by DONNA LONG

My teenage daughter's diagnosis of visual impairment temporarily challenged my vision of her future. Lucy was six months old when we were informed that our daughter was legally blind. I would later discover that my path to acceptance could be best defined by Webster's Dictionary.

Returning home with the news, our friends and family didn't know what to say, and therefore said nothing. Our boys, then ten and seven years old, didn't understand what the fuss was about; their sister was the same as she had been before visiting the doctor in the big city. My husband fled to the normalcy of his office. I knew that I would never experience happiness again – all colour and beauty had left my world with the diagnosis. (*Shock*: "a sudden arousing of emotion or disturbance of mental stability by something unexpected, offensive or unwelcome.")

At first I thought there had been some kind of mistake, that the doctors were wrong. However, in hindsight, there had been signs that Lucy lacked vision; she hadn't tracked us with her eyes, or taken any notice of the mobile above her crib. As parents, we had chalked it up to the fact that babies just develop differently, and on their own timeline. (*Denial*: "an assertion that something is not true, a refusal to acknowledge.")

When, days later, reality set in that Lucy's diagnosis was not an error, I began to believe her disability was my fault. It was something that I had done while I was pregnant; I had eaten the wrong food, had a glass of champagne

at New Year's, my seatbelt had pulled tight stopping at a red light. Maybe it was the bad cold I had caught. (*Blameworthy*: "deserving blame, at fault.")

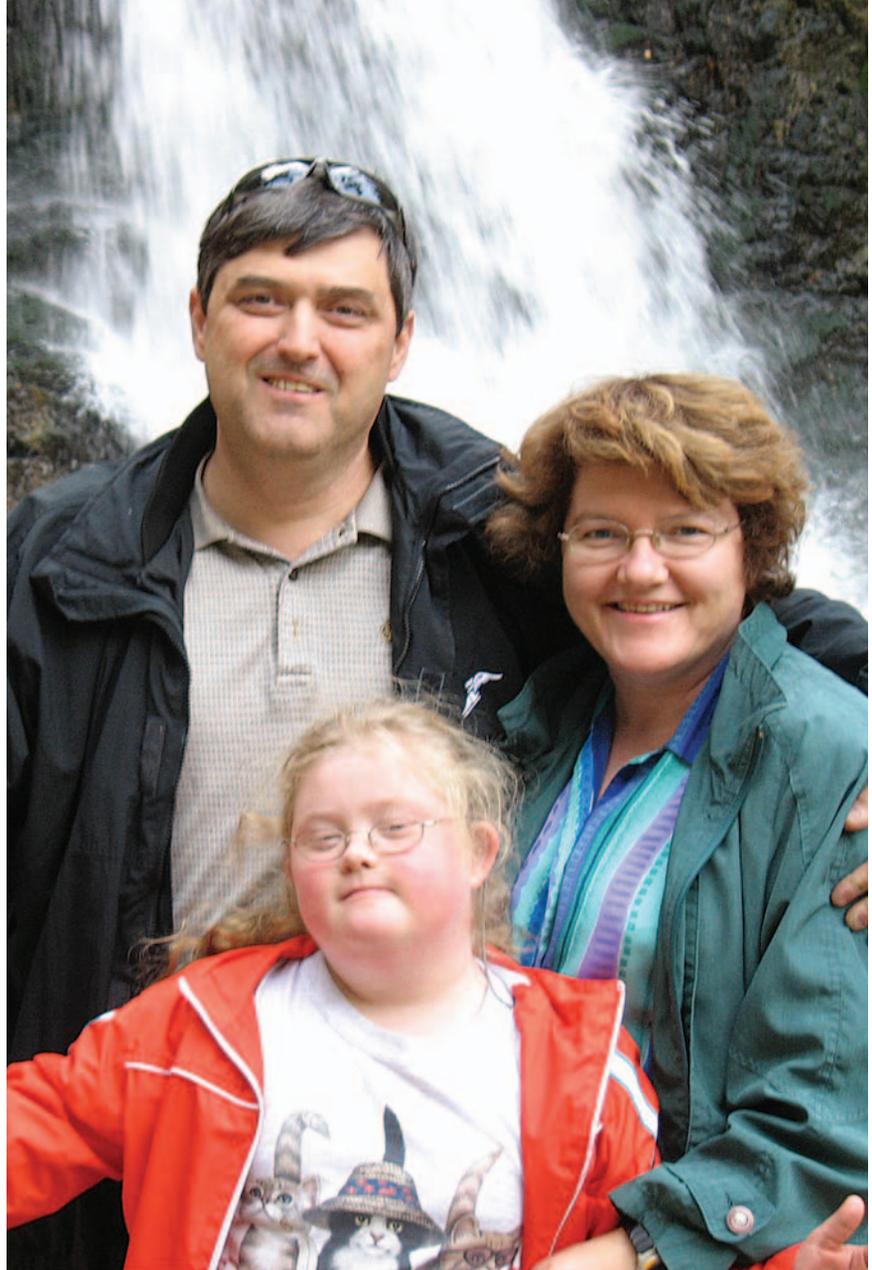
When blaming myself didn't ease my pain, I began to point fingers outward. *This is not the way it is supposed to be in my world*, I thought. In my world, fate had not even dared to rain on my wedding day. Now, my little girl was blind. Fury and a sense of injustice boiled in my veins. (*Anger*: "rage, passionate displeasure.")

Months later, it dawned on me that these emotions were similar to those of the grief process. I was grieving the loss of a child. The child who would have seen my face, pointed out animals in the fluffy white clouds against the bright blue sky – the child without disabilities. In allowing myself to grieve this lost imaginary child, I was not lessening or diminishing my love for Lucy in any way. It was okay to grieve. (*Acceptance*: "a taking or consenting to take something offered.")

The grief process is an ongoing and difficult course, but there is always a reward. My continuing reward is to see my Lucy in her entirety and not just her disabilities.

Children with visual impairments can be "taught to see" and learn to orient themselves within the world. We began vision therapy and were instructed to buy neon lime-green socks to wrap around Lucy's baby bottles. We got black and white contrasting toys, and then shone a flashlight on them in the darkened room. We put black placemats on her highchair tray, then provided white bowls, utensils and toys.

I have found that as I teach Lucy to "see" in her world, she teaches me to "see" in mine. Lucy rejoices in her discovery of emotional colours



The Long family: Phil, Donna, and 13-year-old Lucy.

*"Although the world is full of suffering,
it is also full of the overcoming of it."*

- Helen Keller

and beauty in her world, and mine is now flooded with colours and beauty once again.

Now, at the tender age of 13, Lucy has a crush on a boy. I can't begin to fathom what she sees in her mind's eye when she talks about him, other than to say that it appears to be more beautiful than any multicoloured tropical sunset.

Lucy will never really know that she has a visual impairment, because she will never know anything else. The only person who has had to learn to live with it is me. It was my vision of Lucy's future – and not hers – that was impaired. I had allowed Lucy's diagnosis of visual impairment to temporarily blind me. ■

Like Ability

Learning the ‘How’ of Relationships

The third in a series on Living, Loving and Relating presented by Exceptional Family and Vita Community Living Services, an organization serving adults with intellectual disabilities in the Greater Toronto Area

by CRYSTAL LYNN, KIMBERLY BEATTIE,
and DAVE HINGSBURGER
The Vita Relationship Training Team

A few years ago she said, “My son has so many friends.” Now she is saying, “My son is lonely.” Her shock at the realization that his circle was full of paid people, not friends, was enormous. Now her son expected friendships, but didn’t seem to have the skill to develop them.

Like his mother, he thought that “friends” came to him. They showed up, did what he wanted, meeting his needs asking nothing in return. Over time he, like his mother, came to realize that these were not friends like his classmates had.

No one is going to love your kid just because you do. No one will spend time with your child, without pay, unless your child has a certain set of skills that make him or her desirable to be with. Expecting “friendships” to be gifts out of “pity” and “sacrifice” starts kids with disabilities down a long and lonely road. Likability is a skill! A teachable skill.



It is important to understand that volunteers and staff aren't friends. Never use the term "relationship" when referring to paid people. A volunteer is a volunteer, staff are staff; they are what they are – care providers. While this may seem cold, it isn't. It's accurate. It eliminates confusion and can ensure that the right boundaries are in place between your child and those relating to him from the get-go.

Relationships require many skills. Here are ten that can be taught. From these skills, wonderful friends, loving wives and thoughtful husbands grow.

1 Reciprocity: This is the single most important skill for the maintenance of human relationships. Giving to and getting from indicate a relationship of equals. Teaching your child to give of self is hugely important. Sometimes disability puts children in the place of being constant receivers of time and attention. This can create an addiction to being the center of attention. Children need to be in positions where they "gift" time and attention to others.

2 Trust: Thought to be an emotion, trust is actually a skill. It's an important abuse-prevention skill. Knowing who to trust and how to trust keeps people safe in relationships. Too often, children with disabilities are encouraged to trust everyone indiscriminately. Learning that there are people who manipulate and pretend friendship for personal gain is important.

3 Thoughtfulness: At the core of good relationships is the ability to listen, to take in information and then act in a manner that demonstrates caring. Children can be naturally thoughtful. Remembering that you like blue flowers and pointing them out when you go by one, for example, is a simple gesture on the part of your child



which demonstrates thoughtfulness. You may not perceive it as anything special, but it's really a wonderful moment that ought to be commented on.

4 Approachability: Simply put, don't stink! Good hygiene and attention to grooming are way more important than you might think. Children need a lot of praise and attention for looking and smelling good. Some parents feel that grooming oneself properly is a behaviour that reinforces itself, but it's not. Remember that people with cognitive disabilities are not very good incidental learners,

so they may not pick up smiles of approval or notice social reinforcement. You must tell them, "You look and smell pretty", or, "Wow, you are the best groomed little man in town."

5 Interests and Passions: Small talk is born from big interests. Having something to say is important, and being involved in something contributes to interesting things to say. Notice what your child is attracted to and encourage hobbies and pastimes. Interests developed in childhood are sometimes sustained throughout a lifetime. The pursuit of an interest also can

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develop into interest-specific friendships and naturally occurring similarly-focused social groups. Moreover, people who do things that they are interested in are naturally more interesting to talk to than those who don't.

6 Responsibility: Apologizing is tough, but taking responsibility for things that go wrong is an important relationship skill. The tendency to blame others for one's mistakes, or to blame disability itself, simply shifts responsibility from self to some "other". Saying "I'm sorry" for causing hurt or disappointment is powerful. But the only real apology is change. Apologizing and doing the same thing over and over again is worthless.

7 Assertion: Don't be a doormat! Assertion plays a role in decision-making, negotiation, and even sharing. Stating a preference means being able to put forth what you want. This skill is only learned in an atmosphere of safety. Teasing a child for stating their preferences can be devastating to his or her development. When a child is asked what he or she would like to watch on television and then gets a negative response like, "Oh, no, really, you want to watch that kind of "baby" garbage?", the child is much less likely to contribute in the future. This can lead to a life of passivity and isolation.

8 Negotiation: Any husband or wife in the world can attest to

the fact that negotiation is a complex art. Friendships are destroyed when negotiation isn't employed. The ability to listen and work through decisions conveys a willingness to be flexible. "It's my way or the highway," may be a cute slogan, but it makes for a lousy friend. It's important to have opportunities to practice negotiation; sometimes winning, sometimes giving in, sometimes deciding on something else entirely – these outcomes can be exciting rather than distressing.

9 Sharing: So many people with disabilities learn early on that the lion's share of attention belongs to them. Since some with cognitive disabilities take longer to learn, they are more often the focus of parental attention than their brothers or sisters. Since they are also often the exclusive focus of school meetings, they can develop an odd kind of egocentricity – "If it ain't about me, it ain't worth talking about." Learning to share attention is just as important as learning to share toys.

10 Manners: Sadly, manners are no longer in vogue. Even so, *please* and *thank you* are still "magic words." Knowing how to meet and greet, shake hands and chew with a closed mouth are hugely important skills. There are many phrases that hint at manners like "Gimme gimme never gets" and "Take a picture instead of staring, why don't you?" There is a

certain degree of civility that makes a person more likeable over others.

We'll throw one more in, just for fun...

Humour: Everyone finds humour attractive. Spend time laughing!

Knowing that likability is a skill that can be learned is powerful, good news for parents of all children. It means that parents need to think of and notice relationship skills – simple ones like the ten listed here. In the noticing of these skills can come reinforcement and training. These skills are fun to teach because they focus on the natural parts of loving.

And loving ... well that's in the next issue. ■

Crystal Lynn is a Relationship Trainer and program supervisor at Vita Community Living Services. She is a graduate of the Child and Youth Worker program at Niagara College and has been facilitating Relationship Training classes for over three and years.

Kimberley Beattie is a front line staff member and Relationship Trainer who has worked at Vita for 11 years. She is completing the Developmental Service Worker program at Humber College.

Dave Hingsburger is the director of Clinical and Educational Services at Vita Community Living Services. Dave has written numerous books and articles regarding disability and travels extensively to give lectures and provide consultations.

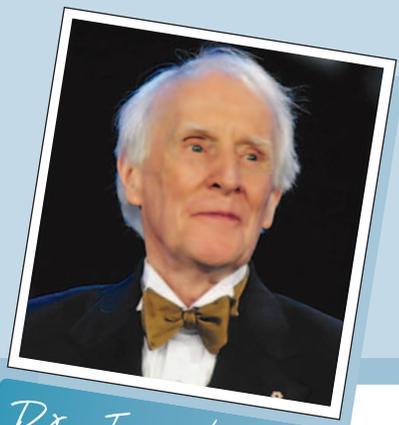


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imprints

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



Dr. Frank Hayden

There's no doubt that the Special Olympics movement was popularized by Eunice Kennedy Shriver, who, as an advocate for her exceptional sister Rosemary, championed the rights of people with intellectual disabilities and was one of the leading forces behind Special Olympics' nationalization. While Shriver is largely recognized as the organization's founder, it was actually Dr. Frank Hayden, of London, Ontario, whose vision and resolve can be credited with Special Olympics' creation.

A graduate of the University of Illinois' Physical Fitness Research Laboratory, Dr. Hayden co-authored the first Canadian study on the fitness of Canadian children in 1966, a project which involved 11,000 children from coast to coast. A few years prior, research conducted on youth with intellectual disabilities had revealed that they were only half as fit as their "typical" peers; a direct consequence, it was believed, of the fact that they were "disabled". Dr. Hayden questioned this hypothesis, and embarked on his own research project. His findings led him to conclude that people with intellectual challenges could become more active and participate in sports, if given the opportunities and skills to do so. Inspired, Dr. Hayden devised a national sports program for people with intellectual disabilities.

"The goal of Special Olympics is to make children fitter, stronger and more capable, and to help them to become better integrated into communities and into their families. The benefits of being involved are fitness, health, self-esteem, and confidence-building. Special Olympics were created for everybody; it's not just for top athletes – everyone should benefit from it. The world of sport is universal."

News of Dr. Hayden's efforts spread all the way to the Kennedy Foundation in Washington D.C. The Kennedys convinced Dr. Hayden to move to Washington to become a director at their foundation. It was during this period that he launched the Special Olympics. The first track and field, swimming, and floor hockey competitions under the Special Olympics banner were held in Chicago in 1968.

In the early 1980's Dr. Hayden founded Special Olympics' Office of International Development. Under his guidance, the organization grew from 15 international affiliates to 50. In 1988, he relocated to Paris to establish and direct the Office of European Affairs for Special Olympics International. In the two years that followed, 13 new national organizations opened in Europe.

In 1990, Dr. Hayden returned to Canada. He served as Special Consultant to Canadian Special Olympics for six years, beginning in 1994. That same year, Maclean's named Dr. Hayden to its Honour Roll of 12 Outstanding Canadians. He is the recipient of multiple awards, and was named an Officer of the Order of Canada in 2000. In 2001, he was appointed a Citizenship Judge by the Privy Council of Canada.

Today, approximately 3.5 million athletes in more than 170 countries are part of Special Olympics. Regional offices span the globe, from Ireland and Egypt, to China and Panama.

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

For more information about Special Olympics in Canada, visit www.specialolympics.ca



Sure I can

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

A Vision That Drives Him



PHOTO: JULIAN HABER

Quebec pop, R&B and soul singer Denis Harting has been described as the little guy with the big voice; despite standing at barely five feet tall, once Denis begins to sing, his presence is overwhelming.

The first time I heard Denis sing, I instantly understood why. It was January 2010, at a Montreal benefit concert for Haiti, and Denis performed together with his 16-year-old daughter, Lauviah. It was a performance that moved everyone to tears and sent shivers down my spine. What made the duo's passion and talent all the more impressive was the fact that both Denis and Lauviah have visual impairments. Lauviah also has autism.

"Singing expands my consciousness," says Denis. "I can show people my soul, using my voice as a carrier. [When I sing,] I usually feel elated, excited, inspired and empowered. Since Lauviah is very energetic, I have a lot of fun singing with her. There's a great collaboration between us!"

A difficult upbringing

Born two months premature, Denis was placed in an incubator at birth. But the very haven designed

to protect him actually contributed to his becoming an "exceptional" person; excessive oxygen in the incubator not only burned his optic nerves, but also contributed to other physical challenges, including motor-skill issues.

Remarkably, Denis is at peace with the accident that changed his life. He harbours no bitterness and actually views the mishap as his destiny. "I've chosen this condition as a soul [before I was born]," says Denis. "I agreed upon it, so the least

I can do is accept it and see the gift in it. I take it as a challenge, a learning experience, an opportunity to grow, to develop other senses and see beyond appearances."

Denis' biological parents – a mother too young to deal with his special needs and a father diagnosed with schizophrenia – could not care for him. At six months old, he was placed in his first of three foster homes. As a youngster, Denis attended the Louis Braille Institute in Longueuil, Quebec, a rehabilita-



Quebec singer Denis Harting

tion centre for people with visual impairments which also served as an elementary and high school. He lived there during the week and returned home to his foster family on weekends.

Despite never having a permanent family, Denis was a happy, carefree child. He had a vivid imagination, loved science fiction, and would fantasize about an alternate world for himself where anything was possible. His enthrallment with sci-fi led him to write stories on the subject, and Denis won several high school writing contests. His greatest passion, however, was music. As a child, he loved listening to the radio and competed in camp talent shows as a teen – easily winning the singing competitions. However, it was in 1990 at the age of 20, that Denis was inspired to take the first step toward fulfilling his dream.

“It was an August day,” he recalls. “I was riding in a taxi, and ‘Vision of Love’ by Mariah Carey came on the radio. I was thunderstruck by the voice that I heard, for its power, soul and tone. That’s when I knew I would follow in her footsteps – it came to me in a flash. From then on, she became my main vocal inspiration.”

Denis was also touched by Carey’s songwriting style. “I felt it was very akin to mine since I was already writing songs back then. Of course, her music and melodies spoke to me profoundly as well. [The experience] was almost mystical, which made me love R&B even more than I already did!”

Inspired by this new energy, Denis began to showcase his talent as much as possible. In 1992, he reconnected with Peggy Roux, a former classmate from Louis Braille Institute. The pair married and, in 1994, they had Lauviah, who inherited her mother’s congenital blindness and was later diagnosed with autism.

In the years that followed, Denis continued to pursue his dream, taking vocal courses under the guidance of Montreal coach, Philippe Parent. He also recorded cover demos and performed whenever the opportunity presented, despite limited funds.

Tragedy strikes

In 1996, the couple welcomed their second child, son Hassan. Hassan was the only one in the family with sight, and Quebec child protection services

“When we were called and told that he was going to be transferred [from the rural hospital to our city’s children’s hospital], a great chill went down my spine, and in an instant I knew he was gone,” remembers Denis. “[That feeling] was only to be confirmed 22 hours later when he finally released himself from that body.”

In the face of unimaginable tragedy, Denis says he “managed to cope relatively well because I adopted a more universal perspective on life and

“I knew Hassan wanted me to move on with my life and be happy, and make my dreams come true. Hassan loved my music and always wanted me to succeed.”

were concerned about his “need” to be exposed to individuals outside of his nuclear family. On the agency’s insistence, the couple sent then six-year-old Hassan to a “mainstream” summer camp. On July 24, 2002, during a camp outing, Hassan drowned in an artificial lake.

death. Death is only another part of life, not the end. And this was not just intellectual for me. I had to really live it, feel it! And so I did, as much as I could. I knew [Hassan] wanted me to move on with my life and be happy, and make my dreams come true. Hassan loved my music



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- Yves Lachapelle Ph.D.
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DAY 2

Best practices in early intervention in children with ASDs and IDs

- Diane Bricker Ph.D. together with Carmen Dionne Ph.D.

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“Even in the darkest of moments,
I have faith that I am
going to get through.”



Sixteen-year-old Lauviah performs with her parents in a Montreal subway station.

and always wanted me to succeed. And so I promised myself to make it.”

Forever looking forward

Nine years after Hassan’s passing, Denis carries on with the very same optimism he embraced as a child. “Music is one of my two passions in life – music, and my faith that there will always be something better ahead,” he says. “Even in the darkest of moments, I have faith that I am going to get through. I [also] have good friends. I have always been surrounded by people who believed in me and my talent.”

Among those who have always believed in him is Peggy. While the couple is now divorced, Peggy continues to work as Denis’ manager, encouraging him to reach his goal of stardom.

“I’ve always been passionate about music, music creation, management,

production, and sound engineering,” says Peggy. “But I’ve become fascinated by Denis more specifically, for his unique voice, charisma, magnetism, immense singing and songwriting talents... it was natural for me to want to join my own talents with his, and take him and us [including Lauviah] to the top. We also write songs together – great songs, and now we speak together at conferences. This tightens our team even more,” says Peggy.

Paying tribute to his idol

Over the years, Denis has been featured multiple times on Quebec television. In 2003, he performed at New York’s Madison Square Garden as part of the New York International Music and Film Festival. The following year, he was invited to perform in Athens at the Special Olympics. Then in 2005, a production company called PI Entertainment held auditions for “The

Reign”, a charity event celebrating Mariah Carey’s inspirational legacy. Denis aced the audition and performed at the show in April of that year at New York’s Lincoln Center for the Performing Arts.

Along with Denis’ successes, there have been several false starts and setbacks. But through it all, Denis perseveres. He and Peggy have launched “Beyond Appearances”, a conference geared for groups and organizations featuring performances by Denis and Lauviah, mixed with inspirational anecdotes by Denis and Peggy, who share their story.

Their goal is simple – to encourage people to see the greatness within others, and within themselves. It’s a message they hope to impart to Lauviah as well. “We want to teach Lauviah to trust and believe in herself, to strive for her own perfection and be the best that she can be,” says Peggy. “To never give up and go to the end of her dreams.”

“We all have greatness,” adds Denis. “We just have to see it in ourselves.”

And that is the vision that drives him. ■

Michael Lifshitz, CA, MBA, works in accounting at McGill University. He is also a motivational speaker and comedian. To learn more about Michael’s endeavours, visit www.michaellifshitz.com.



To hear Denis Harting’s music, visit www.myspace.com/denisharting. Denis and Michael Lifshitz will perform together at “Sure I Can and You Can Too”, a motivational evening at Montreal’s Concordia University on March 8. For details visit www.sureican.info.

Move Over, Craigslist – There’s a New Kid in Town

How one little boy’s needs inspired his parents to help others in a big way

by AVIVA ENGEL

With his golden locks and trendy miniature eyeglasses, two-year-old Zachary Rayment of Toronto instantly stands out from his triplet brothers, Aidan and Aaron, whose identical faces and straight blonde hair make them indistinguishable to the untrained eye. But the adorable little boy’s uniqueness extends far beyond his physical features. Unlike his ‘typical’ brothers, Zachary has cerebral palsy (CP), which significantly limits his mobility and affects his every move – challenges he appears determined to overcome, as he drags himself up the stairs with support, undaunted. Yet perhaps most remarkable, is that the tyke is the star of his very own website, zachslist.ca, a portal created by his parents, Barb De Roo and Simon Rayment, to assist other exceptional families with similar needs.



*Zachary Rayment
at 20 months.*

“Zachary was officially diagnosed as a spastic quadriplegic, meaning his muscle tightness affects all four of his limbs,” says Barb, an early childhood educator who works part-time amidst caring for the triplets and daughters Chloe, 9, and Kate, 1. “His condition is worse than some, better than many, and we consider Zachary to be extremely fortunate as, other than muscular

Simon, who is co-owner of Pandor Productions, an audio-visual equipment and services company. “We need to cart or carry him everywhere we go. He doesn’t eat well by himself. We still spoon-feed Zachary most of his meals like an infant, and have to supplement his diet to make sure he gains weight properly. We’re constantly problem-solving to keep Zachary’s environment

Zachary will require bigger equipment to match his size, as well as ankle-foot orthoses (AFOs) and special shoes. While the Ontario Ministry of Health and Long-Term Care’s Assistive Devices Program subsidizes 75 percent of mobility equipment costs, necessities like a bath seat, crawl trainer, outdoor ramp, and adapted toilet are not covered. Moreover, because much of Zachary’s gear is extremely cumbersome to transport, his parents would like to be able to leave duplicates in places that Zachary frequents, like his daycare and grandmother’s house.

Perfectly good children’s equipment was gathering dust in people’s basements and garages.

issues, his brain function seems to be intact. He is smart and social, sings songs to himself and wants to sleep in our bed at 3 a.m., the same as any toddler would.”

Zachary was diagnosed with CP at 11 months old. Born two months premature and weighing between 2.5 and 3.1 pounds, the triplets underwent routine screening in the initial months following their birth. A head ultrasound revealed a white shadow on Zachary’s brain, which doctors diagnosed as Periventricular leukomalacia, or PVL, a form of brain injury that often leads to epilepsy or CP. For his parents, the diagnosis was difficult to digest. “It was a very hard idea to get used to,” reflects Barb. “I repeatedly asked the questions I felt were very important at the time: Will he walk? Will he run? Will he play soccer with his brothers? The reality slowly sunk in, though. We began to realize our child would always have special concerns, and though he may indeed ‘play’ soccer, he will probably always move a little funny, and he will likely play in a league with other children more like him.”

For now, however, Zachary is not yet able to stand independently. “He can sit on his own for short periods,” notes

physically safe, and yet still stimulating enough for a bright two-year-old. We also need to keep him safe from his brothers and his peers, but allow him to socialize.”

Prohibitive equipment costs

Zachary is also dependant on a significant array of adaptive equipment – equipment that comes at prices ranging anywhere from \$300 to \$2500. There’s his special stroller which can be converted with a base to support him while eating so that he does not choke, a stander that enables Zachary to bear weight on his legs, a walker, two chair inserts, arm braces to stretch his muscles, an exercise ball for physiotherapy, and an adapted potty system. “We’re currently keeping our eyes open for a bath seat that will allow Zachary to sit in the tub with his brothers, and a crawl trainer to encourage him to bear weight on his arms and build strength in them so he doesn’t collapse on his head, as well as a seat that helps Zach to sit upright by pushing his shoulders forward, so we can leave him to sit independently,” says Barb.

And those are only his current needs. His parents anticipate that, as he grows,

“Equipment is very expensive,” says Barb. “There are charities that will help with other [non-mobility] equipment costs, but ... if you spend the [funds] on a crawl trainer, you may not have enough for the stair-lift you need later on. We’ve met parents carefully saving their pennies and trying to decide which of the astronomically-expensive pieces of equipment would most help their child.”

On the flipside, the couple have also met parents “who have thrown away used wheelchairs and walkers that could have been donated for re-use, simply because they didn’t know how to pass them on,” says Simon.

Out of a joke – a website is born

The realization that perfectly good children’s equipment was gathering dust in people’s basements and garages struck a chord with Barb and Simon, who had searched popular classifieds websites for used gear for Zachary, unsuccessfully. “Kijiji has a category for ‘health and special needs’ items, but trying to find the few pediatric equipment listings inside the hundreds of listings for adult equipment is challenging,” says Barb. “Craigslist doesn’t even have a special needs category, so that makes things even trickier. We



PHOTO: AMARA STUDIOS

The Rayment family: Barb and Simon, with daughters Chloe, 9, and Kate, 1, and two-year-old triplets Aidan, Aaron and Zachary.

were joking that Craigslist was in need of a list for Zach – and that’s when Zach’s List was born. Simon and I decided that this was an opportunity for us to help. We could create a site for families, aimed only at children’s equipment and use one of the best resources available – each other.”

Zach’s List was officially launched in October 2010. Tagged as “Your Pediatric Equipment Exchange Source”, the website is an online community where parents and caregivers may connect and reduce equipment expenses by buying and selling second-hand items through free classified ads.

“It was our experiences with Zachary that were the inspiration for this site, but this site is not ‘for’ Zachary,” emphasizes Simon. “It’s for other families, like ours, who are trying to give their kids the best they can. Families trying to balance *all* the extra costs, be they special schooling, physio-

therapy, extra help around the house, special footwear, adaptive toys, home renovations, hearing and sight aids, programs to enhance development, or pediatric equipment.”

As a non-profit endeavour, all aspects of Zach’s List, including site design, maintenance and related promotional material, are entirely sponsored by local companies who believe in the cause. In addition to the trading post, the site also features a monitored

discussion forum where registered users can exchange ideas. “The other important thing we families have to share with each other [besides equipment] is knowledge and experience,” says Barb. “Most [exceptional] parents who have been journeying through the system for a while are a wealth of information for parents just starting the trip. The discussion board is a safe place for families to ask questions, share experiences, make friends, and vent.”

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PHOTO: AMARA STUDIOS

Making time amidst the busyness

With careers and five kids to care for (four under age two), it's a wonder Barb and Simon have time to eat, let alone to manage their website. "It is true that we're extremely busy," says Barb. "But the time just seems to materialize from somewhere – instead of a shower, between diapers three and four, while four kids sleep and one sits on my lap watching Elmo!"

In the short time that Zach's List has been online, the feedback has been "amazing," says Simon. "We've received many positive and thankful messages from parents and professionals. We've already seen many children get equipment they really needed, and families feel good about finding a place to give their used equipment; where they know it is appreciated and is making a difference in a child's life. We have also made amazing connections with other families."

At only two years old, Zachary, the adorable little boy with golden locks and miniature eyeglasses, has years to grow before he learns about the website that bears his name and the lengths to which his parents have gone, to help him and others reach their potential. "We hope Zachary takes from our efforts that you can always choose how to play the hand you have been dealt," says Barb. "Having a child with special needs can be very difficult on a family, especially emotionally. But we can choose to be grateful for the blessings we do have, and try to help others – many of whom are in situations much more difficult than ours. The very least we can do for these families is to help them find the tools they need to make life the best it possibly can be." ■



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