

FamilyTies

A Troy Media Publication

Navigating the learning disabilities maze

An Alberta family's struggle with autism

Overcoming the painful LD stigma

Couple makes peace with disturbing diagnosis



Navigating the Learning Disabilities Maze

By Bob Weinstein

FAMILY TIES EDITOR-IN-CHIEF



Welcome to Family Ties — a Troy Media Corporation quarterly special section about how families cope with crises.

The stories combine real-life sagas of families with advice from credentialed experts.

This issue of **Family Ties** focuses on *learning disabilities* — a cold and off-putting term.

The Learning Disabilities Association of Alberta defines them as “a number of disorders that may affect the acquisition, organization, retention, understanding or use of verbal or nonverbal information. These disorders affect learning in individuals who otherwise demonstrate at least average abilities essential for thinking and/or reasoning.”

MORE DEFINITIONS

In the US, the National Institutes of Health defines learning disabilities as “a disorder that affects people’s ability to either interpret what they see and hear or to link information from different parts of the brain. These limitations can show up in many ways: as specific difficulties with spoken and written language, co-ordination, self-control or attention. Such difficulties extend to schoolwork and can impede learning to read, write or do math.”

The Calgary-based Rocky Point Academy offers a broader, non-specific definition: It says that those diagnosed with LDs are “intelligent, bright or even gifted individuals that for no obvious reason, struggle to learn in reading, writing, spelling, math, focus, organization, time management or social skills.”

Rocky Point’s description captures what **Family Ties** writers learned from interviewing parents of LD children: learning disability describes normal children who learn differently and who don’t fall into a statistical norm.

THE PROBLEM IS THE SYSTEM

Diane L. Duff, director of Ottawa and Toronto-based Aldridge-Duff, a firm that provides educational services to students with reading disabilities and dyslexia, says that the term learning disabilities has always troubled

her because it categorizes based on pre-established and organized ways of structuring schools and education.

“If we say a person has a learning disability, we’re saying he or she doesn’t fit into the system,” Duff explains. “Maybe it’s the system that has the problem. If we focus more on the child and try to teach children, rather than teaching curriculum, we have less need for these terms.”

But although experts are still bewildered as to what learning disabilities are all about, it hasn’t stopped the growth of mini industries to treat and teach the learning disabled.

In fact, learning disabilities and disorders have become specialties all their own; educators have built training programs around dysfunctional (another dangerous word) learners and, every year the publishing industry turns out even more books, magazines and newsletters on the subject.

Last but by no means least, the pharmaceutical and organic medicine folks are producing drugs and potents, synthetic and natural, to treat many learning disorders.

So learning disabilities also translates to moocho bucks.

CAN’T ARGUE WITH NUMBERS

Statistics are the indisputable evidence, the steel girders, upon which LD programs are created. Western cultures are more comfortable putting human beings in cubicles and categories, assigning them labels and numbers because it’s easier to understand them. Here are the hard numbers fueling the learning disabilities industry.

In March 2007, the Ottawa-based Learning Disabilities Association of Canada (LDAC) released a three-year study on learning disabilities. Among its disturbing findings:

- Approximately 28 per cent of the learning disabled (between the ages of 20 and 29) do not complete high school.
- Nearly 1/3 of parents with learning disabled children can’t afford learning aids to help their children succeed academically.
- Learning disabled students achieve less than Level 3 in prose literacy — the basic requirement for moving up the educational ladder.

The National Institutes of Health estimates that about 15 per cent of the US population is affected by learning disabilities, mostly with problems in language and reading.

In 1980, autism was considered a rare disorder in the US, with an estimated two to five per 10,000 people. Currently one in 110 children in the US is on the autism spectrum. Prior to 2009, the autism prevalence rate stood at one in 150 children.

CONFUSING HODGEPODGE OF TERMS

Even with hard numbers, none of which are definitive, “learning disabilities” are as confusing as ever.

If the experts can’t get their heads around the term, imagine how difficult it is for families trying to get help for their children diagnosed with learning disabilities or disorders?

Parents’ quest for understanding is the leitmotiv running through the **Family Ties** stories you’re about to read. The parents, whether in Alberta or Manhattan, are the stars in these real-life stories. They are the relentless, unstoppable engines responsible for getting their children the help they need and deserve. Without them, their children would fall through the cracks, and lie fallow in a forgotten field of ignorance. Because of their devotion and hard work, their children have flourished, evolved and became productive members of society.

The pity is that they had to work so hard to give their children the options, choices and learning materials to which everyone is entitled.

THE SOLUTION

Children — people — shouldn’t be stigmatized because they’re different.

The solution may be that the standards and criteria defining the normal learner should be scrapped because they are too rigid and inflexible.

The writers and editors of **Family Ties** don’t have the answers. Our goal is to open the issue for debate, which is the first step leading to change. ●

FamilyTies

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A mother's battle to educate her learning disabled son

By Meryl D. Pearlstein
FOR FAMILY TIES

Meryl Pearlstein's story will resonate with every parent of a learning-disabled child. It is about how a public relations executive and her husband, James Wacht, a real estate developer, fought the system — and advocated for their son — so he could get the best education possible, and have what all parents want for their children — a fulfilling and meaningful life.

My son Evan was the class clown in third grade. He was amiable and funny but often unfocused and distracted. It took an astute teacher to recognize that this behavior was probably a mask for a learning disability that affected his ability to process verbal and written information.

Four years earlier, Evan had been told to repeat nursery school — not because there was a learning issue but because the school believed that late-birthday boys were generally immature and that extra time would help establish stability and focus.

Thus began our journey into the world of learning disabilities and education, wending our way through a process that was often filled with guilt, frustration and anger, as my husband and I tried to figure out what our son was all about and how we could help him.



Meryl Pearlstein and Evan trekking through woods

When first confronted with the possibility that Evan suffered from a learning disability, we experienced a full range of emotions, from disappointment (What, our beautiful son isn't perfect?), guilt (What did we do wrong? Shouldn't we have noticed this sooner?) and frustration (Why are so many so-called experts telling us so many disparate things?) to fear (Will our son forever suffer a stigma of being learning disabled?).

THE AWFUL STIGMA: "SPECIAL" KID

On the recommendation of a parenting organization, we began to investigate private schools with smaller class sizes. We desperately wanted to keep Evan in a mainstream school so that he could escape being labeled a "special" child.

A preliminary evaluation indicated that Evan's learning disabilities were confined to language processing: He had no attention deficit disorders or physical issues, and he appeared bright and engaged. We transferred him in fifth grade to a well-regarded independent school that was highly structured and had small class sizes.

At first, Evan did passably well, but during his third year he began to really struggle, and his self-esteem and grades plummeted. The school offered only minimal learning support. To remedy this, we tried private tutoring with a learning specialist as well as a program designed to improve his listening comprehension. Nothing helped. Our daily conversations were filled with self-doubt and expressions of futility as we watched Evan continue to struggle with his classes. Worse still were the stressful evenings we spent at home helping Evan study for tests and complete his homework. Often these evenings would end in arguments and tears.

ACCEPTANCE OF LD DIAGNOSIS

We eventually realized that Evan's education required an acceptance of his LD and the development of strategies to deal with his issues. Equally important was the realization that Evan needed an environment that would support and encourage him so that he could emerge from his school experiences with his ego strong and his self-esteem intact. Our quest, then, was to better understand his disability and to find him an appropriate learning environment.

The next step was having a professionally administered psychological and learning evaluation performed on Evan to

document his learning disabilities and offer recommendations for accommodations or extra assistance. The full diagnosis was “reading disorder, disorder of written expression and mixed receptive-expressive language disorder.”

MORE TESTS AND INTERVIEWS

Armed with the report, we visited our city’s Committee on Special Education (CSE), part of the Department of Education, where Evan was further tested and interviewed in order to identify a public school with appropriate learning resources. The schools suggested were ostensibly to help with greater one-on-one teacher-student contact and individualized learning. Unfortunately, the ones with available spots had classrooms with more than 30 students and no real provision for addressing Evan’s specific language processing issues.

Increasingly frustrated and nervous, we chose to explore the few private schools that focused on learning disabled children. In general, these schools had smaller classes and taught students according to their learning disability. The faculties at these schools were also trained in LD education. Our interviews were filled with answers, rather than questions, with Evan looking like an “opportunity” rather than a “failure.” As we toured the schools and observed the teachers in action, we actually smiled. We knew that we were finally heading in the right direction. These were places where Evan could get the support and guidance he needed.

HIT THE JACKPOT

We felt we had won the lottery when Evan was accepted to Winston Prep, a private middle and high school in New York City developed for LD students. The school’s academic approach was enlightened, modeled on a philosophy of personalized education with children grouped by how they learn instead of on an age-based, one-size-fits-all learning curriculum. The good news was that due to several US Supreme Court decisions dating from 1993, funding could be secured for any child requiring special education within the school system. By first considering all public school options proposed by the CSE and then determining together with the CSE staff that a private school could better satisfy the needs of our child, we had the opportunity to obtain funding to help defray the cost of Evan’s need-focused education.



Meryl Perlstein and husband James Wacht; Evan and younger brother Elias

The many meetings with the CSE, psychologists and schools created a fair amount of stress within our family. Because my husband and I both worked full time and had little time to wade through the red tape that the funding process required, we engaged the services of a lawyer who specialized in obtaining tuition support. For us, it was worth the \$2,500 investment per year; however, the process is something that anyone with the time and patience could undertake. Given that Winston’s tuition was significantly higher than that of a mainstream private school, as it included one-on-one learning support services, it was important for us to obtain financial assistance. We secured a refund of nearly 75 per cent of Evan’s tuition at Winston. (While current tuition is \$46,500, the typical Winston family pays about \$16,500 thanks to a variety of funding sources.)

CHANGING DIRECTIONS AND SUCCESS

From our perspective, the move to an LD school was right for our son. Once we understood that his academic failures were not due to a lack of desire or motivation but rather because of a genuine problem, we were able to accept him for who he was and not get upset with him for who he wasn’t. From Evan’s point of view, it was an embarrassment going from a “normal” environment to one where

children were teased by outsiders for being “retarded” or for going to a “special” school.

“I’M NO RETARD”

At times, his younger brother, Elias, was equally cruel, calling Evan a “retard” and other names whenever they fought. We were fortunate that Evan had a strong sense of self and a large network of friends from previous schools, all of which helped him transition with minimal trauma. As parents, we were open with Evan so that he always understood the reasons behind this type of education as well as its value, and we were equally open with our friends, most of whom had no experience dealing with LD children.

The five years that Evan spent at Winston, from 8th through 12th grade, were filled with successes as well as challenges. Motivated by a supportive and enlightened faculty and administration, Evan began to flourish. He built a network of friends at Winston that included both students and teachers. Outside of Winston, he was able to joke about being at a “special” school, referring in a level-headed way to his own idiosyncrasies as “Winston moments.”

Evan also developed an affinity for working with children and took a job at a summer camp, where he became one of the most popular counselors. The school encouraged him to continue his education at a higher level, guiding him to look at colleges and universities that offered appropriate learning support services. His teachers also encouraged him to further his work with children.

ON THE ROAD TO A PRODUCTIVE LIFE

After the initial academic stumbles from nursery school to an inappropriate mainstream middle school, Evan had found a school that supported and developed his academic abilities, his ability to self-advocate and his self-esteem, all critical for him to approach college and adulthood with confidence.

Currently a freshman at the University of Vermont, Evan has access to support services and has met with his professors to disclose his learning disabilities—or, as he calls them, his learning differences. Thus far, he hasn’t asked for any special assistance, but he won’t be shy about seeking it out if needed. The boy who once could not master a standardized test or a homework assignment without serious angst and many tears is now preparing for a career in the noblest profession of all: teaching. ●

Lifelong burden of overcoming LD stigma

By Doug Firby
FAMILY TIES SENIOR WRITER

Colleen Wall grew up on the East Coast of Canada on tiny Bell Island near the Newfoundland capital city of St. John's, believing from her earliest years that she was inferior — dumber — than her two brothers, and most of her classmates.

Colleen struggled in school, and her teachers judged her to be lazy. "People told me I wouldn't amount to anything," she says, her eyes welling red even now, more than three decades later, at just the memory. Her Grade 12 biology teacher went so far as to describe her as the "least likely to succeed of her entire class," an assessment that stings as though it was delivered yesterday.

Colleen's father was an alcoholic, and abandoned the family when she was just four, leaving her mom, Sheila, to a life-long struggle to provide for her children. Colleen's brothers, one younger and one older, were "book smart" and Colleen became accustomed to hearing her

mother scold them for just getting 90s, when a passing grade of 50 was OK for her.

Yet, in spite of classic symptoms of a learning disability, Colleen went undiagnosed, and her family maintained a stony silence about a problem they didn't understand. Her mother did the only thing she knew — she got her daughter heavily involved in sports "because that is what I was good at."

PASSION FOR SPORTS

That passion for sports brought her to Calgary at the age of 18 to pursue a career in figure skating. Later, she tried ice hockey, training with players who went on to form the core of Canada's gold medal women's Olympic hockey team.

Colleen learned to hide her disability well. But one day, during a 6,100-km driving trip from Calgary to Newfoundland, her mother saw that her 23-year-old daughter couldn't write a simple post card, and finally suggested she get some help. "That was the only time she ever said anything to me about it," Colleen says.

Colleen's story is sadly typical of the stresses families face with children who have learning disabilities.

Anne Price, executive director of the Calgary Learning Centre, says the stress of having a learning disabled child can be overwhelming, leading to higher-than-average rates of marital breakdown. "It takes a lot of energy," to work with LD children, and parents often disagree on the best way to support them. Often there are nightly tears and tantrums as frustrated LD children and their parents battle their way through homework.

RUNS IN FAMILIES

Worse, because LD often runs in families, one parent displays the same impulsive and disorganized behaviours that the child does, leaving the other parent with the entire burden of keeping the family together.

As with Colleen, parental denial is typical when a child is diagnosed with LD, followed by a period of grief. The Learning Centre, as with many agencies across North America, focuses on providing all-important emotional support to the entire family.



Colleen is fortunate in that she has met Darcy Smereka, a man who understands her life-long challenge and gives her the support and understanding that she did not find in previous relationships.

Dr. Betty Osman, psychologist on staff at the White Plains Hospital Center, in White Plains, New York, outlines the challenges parents face: medical and educational decisions, financial pressures and time constraints that can disrupt a career. Meanwhile, parents must deal with personal disappointment, anger, self-recrimination and blame. Often, parents of undiagnosed LD children go so far as being punitive with their child, attributing behaviour to laziness, resistance or defiance. Not surprising, childhood depression and low self-esteem are a frequent outcome.

BURDEN TO SOCIETY

Colleen's traumatic experience is echoed by Ann Mock, who grew up in Salt Lake City, Utah, with disabilities in math, reading and writing. "My second grade teacher told my mom to lock me up because I would be a burden to society," she says.

There was little support from her parents, who were both alcoholic.

"My self-esteem has always suffered," says Mock, who, at 47, has never married. "I feel like a failure in life."

Yet Price notes that, with proper support, LD children can exceed at extraordinary levels. With modern techniques, she says, "There's so much hope" these children can reach their full potential.

Colleen is one such example. After her diagnosis, she went on to enrol in St. Francis Xavier University in Antigonish, N.S., and

do it, she says, because of all those challenges she's overcome throughout her 35 years. "The thing I gained from my disability is my hard work ethic."

It's complicated, though. Her mom, who worked so hard for her three children, lives in Colleen's Calgary home, and Colleen will have to sell that house to pay for her educational goal. Colleen has had many sacrifices of her own — like marriage and a family.

"In my life, that was the thing that I gave up the most — having a relationship."

At age 35, she has met a man who finally understands her life-long challenge, a recruiter at another Alberta post-secondary school. He is offering her the support and understanding that previous relationships never did.

Colleen has devoted countless volunteer hours to helping others who are going through what she did, speaking publicly about her struggle. Sadly, she says, although she believes her mother is proud of her, she's never gone out to hear her daughter speak.

QUIETLY SUPPORTIVE FAMILY

Although Colleen's family was "quietly supportive," Ann's family was so distant, she has no relationship with them at all.

"I have one brother. He can't be bothered with me," says Ann. "I also have three half-brothers and two step-brothers. I don't have anything to do with them."

Most heart-wrenching for Colleen is watching her older brother, Raymond, who

earned an honours degree in sociology. "I graduated at the top of my class."

With her older brother's help, she landed work in the oil industry in western Canada, but found it hard to break into her chosen career. Finally, she deleted her LD history from her resume, and landed a job interview with a community college in Alberta. She broke the news of her disability during the interview, but so impressed the hiring panel, that she works today as a recruiter for the college.

Now she's ready for her next big challenge: pursuing a Masters degree. She knows she can

live in Houston, going through denial over the apparent learning disabilities in his 14-year-old daughter.

"He hasn't learned enough about me to figure out how he can help her," says Colleen. "She's getting into trouble in school...I'm, like, how do you not see it?"

Ann Mock, too, has devoted her life to helping others battling LD, choosing a career in special education. She pursued a career in special education.

"I went into Special Education because I didn't want any other student to go through the hell I went through as a child." ●

SIX COPING TIPS FOR PARENTS

If you suspect your child is suffering from a learning disability, don't stop with a teacher's opinion. Most cities offer services to help diagnose children and offer support to families. Here are some great coping tips from Helpguide.org:

- 1: Emphasize healthy lifestyle habits. Make sure your children eat well — a diet full of whole grains, fruits and vegetables and lean protein. Ensure they get enough sleep so they can focus on learning new things. Make their sleep schedule (bedtime and wake time) consistent. And, regular exercise can help your child stay alert and attentive throughout the day. You can also encourage your child to have healthy emotional habits, by giving them outlets for expressing their anger, frustration or feelings of failure.
- 2: Take charge of your child's education. Learn the specifics about your child's learning disability; research treatments, services, and new theories, and pursue treatment and services at home. Recognize the limitations of the school system.
- 3: Work with school. Your child may be eligible for many kinds of accommodations and support services, but the school might not provide services unless you ask for them. When meeting with school officials, clarify your goals; offer new solutions (Do your research and find examples of what other schools have done); keep focused on your child's needs; stay calm, collected and positive; and be as persistent as you are patient.
4. Identify how your child learns best. You can help your learning disabled child by identifying his or her primary learning style: Is your child a visual learner, an auditory learner, or a kinaesthetic (has to be constantly moving) learner? Once you know, you can take steps to make sure that type of learning is reinforced in the classroom and during home study.
- 5: Think life success, rather than school success. Your child's life success depends, not on academics, but on things like a healthy sense of self, the willingness to ask for and accept help, the determination to keep trying in spite of challenges, the ability to have healthy relationships with others, and other qualities that aren't as easy to quantify as grades and SAT scores.
- 6: Take care of yourself. You need to be relaxed, focused, and positive in order to provide the encouragement, support, and love your learning-disabled child needs.

Often, parents of undiagnosed LD children go so far as being punitive with their child, attributing behaviour to laziness, resistance or defiance.

Eli's parents make peace with a disturbing diagnosis



Eli writing a story for his website, CareForNature.org

Twelve-year-old Eli has a lot on his mind. He worries about global warming and the state of the environment. And don't get him started on the dismal results of the December 2009 Copenhagen Climate Conference, where the world's decision-makers met to forge sustainable environmental policies.

Eli does more than talk about these serious global issues. With the help of his father, Jeffrey, a photographer and freelance editor, and his mother, Allyn, a graphic designer, Eli created the CareForNature website (www.carefornature.org) in 2006 (he was 8 at the time) to rally support and focus attention on the importance of saving the planet.

It's an awesome task for anyone, but not for this determined boy, who's convinced he can trigger change by telling people the environment is in bad shape and, more importantly, what they can do to make the planet a more habitable place to live.

As CEO of CareForNature, Eli vehemently believes that protecting the environment is far more than an urgent mission, but the morally correct thing to do. And it troubles him deeply that he can't devote all his time to running his website, posting environmental news and writing his blog.

Like many kids his age, most of his waking hours are spent in school.

But unlike most kids, school is not just a five-day-a-week chore, but another project he feels compelled to devote all his energy and attention to. In fact, there aren't enough hours in a day to accomplish all the things he feels are important.

AMONG TOP FIVE STUDENTS IN HIS CLASS

Eli is in the sixth grade at a nearby public school, within walking distance of his Brooklyn home. He ranks among the top five students in his class, excelling at math and science.

But being an exceptional student and dedicating himself to a noble environmental cause don't make him happy. The problem is that Eli is a perfectionist who obsesses over everything he undertakes, and he can't accept the fact that perfection is an elusive goal, beyond his reach.

His teachers and parents can't convince him of that fact of life — and they never will.

Unlike most kids his age, Eli has no time for play and horsing around. Life is a serious proposition for this intense little lad, who doesn't know what it is to lighten up. That's because Eli is not your average 12-year-old. He thinks and acts differently, has little — at best marginal — contact with other kids his age, feels more comfortable around adults, and, for the most part, lives in his own private world.

Jeffrey and Allyn have been trying to understand Eli's world since he was diagnosed with pervasive development disorder, better known as PDD in the learning-disabilities community.

PDD is a vague umbrella term encompassing five different conditions — Asperger's syndrome, autistic disorder, childhood disintegrative disorder, pervasive development disorder not otherwise specified and Rett syndrome. They're lumped together because no clear diagnostic boundaries separate them, yet they all share common symptoms involving communication, motor and social interaction skills.

Looking back, Jeffrey recalls that even as an infant, Eli was different.

"He was always sensitive to emotion and movement," he says. "He wasn't as well-coordinated as other kids his age, and he wasn't speaking much."

But the couple reasoned that not all kids mature at the same rate. Maybe he was just a late bloomer. Eli was far more than a late bloomer.

By Bob Weinstein
FAMILY TIES EDITOR-IN-CHIEF

It wasn't until Eli attended preschool at age 3 ½ that his teachers spotted problems. Eli's aloofness and disconnectedness with teachers and other kids were the tip-offs.

The school advised the couple to have Eli tested. That's when Jeffrey and Allyn were confronted with the harsh, disturbing truth. Extensive oral and sensory tests by an experienced psychologist confirmed the PDD diagnosis.

It was not a diagnosis the couple took well. "Accepting it was the toughest part for us," says Allyn.

Jeffrey nods in agreement. "Our first reaction was very profound and startling," he says. "First we denied it, which is a classic reaction. 'This is our child, we don't believe it.' We felt knocked down and stunned all at the same time."

This wasn't in the couple's game plan.

Even in that brief and futile state of denial, they knew that the diagnosis was correct. The evidence was there; it couldn't be disputed.

They also realized that wallowing in denial was useless.

As soon as the couple made peace with their situation, the unspoken accord between them

was that they would do everything humanly possible to give Eli every opportunity to be the best he could possibly be. They had no idea what that meant — and still don't. But to this day, it's still their game plan.

WINS AWARD FOR RECYCLING PROGRAM

And a good plan it is, because Eli continues to surprise and amaze them in some extraordinary ways. Aside from being an honors student, Eli, in his own way, is helping to make the planet a healthier place to live. Recently, his school gave him an award for launching a recycling program.

With these stunning achievements — and nine years after Eli was diagnosed with PDD — Allyn and Jeffrey have no idea what Eli's future holds.

While Eli's future remains a blank book, uncharted terrain, his profound accomplishments are due to this couple's unstoppable drive to open every door available.

Allyn credits her husband for most of Eli's achievements, because he has devoted a significant portion of his time not only to studying his disorder, but also to spending time working with him.

Since Allyn works in an office and is away most of the day, it is Jeffrey, as a freelancer working out of his home, who has devoted countless hours — time that could be translated into thousands of dollars in earnings — to researching Eli's disorder and pursuing options for him.

But it was not a difficult judgment call for him. While the couple could have used the extra income, they felt their son was a more important priority. If they weren't going to advocate on their son's behalf, who would?

NO CURES, ONLY TREATMENT

So, life goes on for this tight-knit little family. They have no illusions or fantasies about the future.

They've learned that it's dangerous to set long-term goals for Eli. "We've trained ourselves to think short term and take it one day at a time," Jeffrey explains. "It gives us time to check ourselves."

Pausing for a few seconds to gather his thoughts, Jeffrey adds: "I think it's a bad idea to put high-mark goals on kids, and then drive them toward them. How can parents possibly know what their children are capable of, when every kid is different?"

Jeffrey and Allyn's philosophy: "We keep our heads down, forge ahead, do our best, and see what happens."

The couple has made peace with the fact that there will always be surprises. Eli likely will continue to do well in school — even rack up more awards and honors. But they also know that there are no cures for Eli's condition. Only the symptoms, which vary from child to child, can be treated.

INCONSISTENT AND ERRATIC BEHAVIOR

And they realize PDD will cause Eli to behave in unpredictable, inconsistent and erratic ways.

His moods and awareness levels always will unexpectedly spike, which is very typical of autism and PDD.

"One minute, Eli's very precocious for his age; the next minute he'll lie down on the ground and have a temper tantrum like a five-year-old," says Jeffrey.

"Life will always be very challenging for us," adds Allyn.

"The idea of not knowing who will show up at the dining-room table will always be hard for us to get used to," says Jeffrey. ●



Eli paints banner for global warming rally.

An Alberta family's struggle with autism

By Judy Monchuk

FAMILY TIES SENIOR WRITER

Frank Rosica's mother was pulled aside on his second day of preschool with the kind of teacher's comment that sends a chill through every parent: "We have a problem."

Little Frankie wasn't paying attention, but in a way that was different from other children. The teacher thought that the actions she saw in the precocious four-year-old fit the symptoms of autism.

"I started bawling," says Sandra Rosica of that autumn day in 1997. She went looking for information and found almost nothing. Her favourite parenting book had one paragraph on autism. The Internet, a relatively new source for data then, was of little use.

The developmental disabilities that fall into the category called autism spectrum disorders all affect how the brain handles information.

About one in 165 Canadian children has autism conditions that affect how he or she communicates with others. Some don't speak. Others make blunt statements that are wildly inappropriate. Many fail to make eye contact, and some don't like to be touched.

Sandra's family doctor referred her to a pediatrician who quickly had Frank booked in to meet with an assessment team of specialists at the Calgary Children's Hospital. Every day for a week, the little boy spent hours with a clinical psychologist, a speech therapist, an occupational therapist and a physiotherapist. By the spring of 1998, he was diagnosed with the type of autism called pervasive developmental disorder—not otherwise specified, or PDD-NOS (see page 16).

While far more is known today about autism than when it was first labeled in the 1940s, there are still more questions than answers. Families with an autistic child face a confusing, emotional and expensive road. (See page 18.)



The Rosicas: Frank, Sandra, Robert and Sergio.

Today Sandra and Sergio Rosica are the parents of two high-functioning autistic teenagers — Frank, 16, and his 13-year-old brother, Robert. While life these days is relatively settled for the family, it hasn't always been that way.

When Frank was diagnosed, autism was believed to affect one in 100,000 boys.

AUTISM DIAGNOSIS FEARED

The Rosicas immediately worried that Robert could also have autism too. Nurses teased the couple that they had better chances of winning the lottery. Within a year, the odds were revised to about one in 1,000 — and have grown even greater since. Sandra's third pregnancy ended in miscarriage, but doctors told her that if she had given birth to a third son, his chances of being autistic would have been one in three.

Robert's autism proved to be very different from Frank's. He liked to roughhouse and cuddle, but there was a lot of frustration within the small child. Where Frank was very vocal in English and Italian, Robert spoke only a handful of words. Then one day, he stopped speaking and started screaming.

Both boys liked order and detail. Pillows on their beds needed to be arranged in a certain way. Toilet paper could only go over. Rows of Hot Wheels cars were lined up in specific patterns: Frank's cars would all be placed at the same angle facing the same direction; Robert's cars would also face one direction, but would include groupings by colour. He would line up dozens of dinosaurs at a time and could immediately tell if one was missing.

SEARCHING FOR A DIAGNOSIS

Although Robert could not be officially diagnosed with autism until he was four years old, he was only three in late 1999 when he began the same battery of tests and assessments that his brother had taken. This time, though, both boys also went to see a geneticist. They went through blood tests and CAT scans to see if there was some other information that could help a medical diagnosis. Doctors found nothing except that both had brilliant blue eyes, an oddity since Sandra's eyes are brown and Sergio's are green.

At age four, both boys were extremely low functioning when they were first tested for comprehension. Frank was at one percentile for his listening and communication abilities, meaning 99 per cent of other children were having an easier time with comprehension. Robert's test scores were in the two percentile range.

The Rosicas soon had boxes filled with test diagnoses, interviews and prognoses. Both boys were placed in intensive preschool programs designed for autism spectrum disorders. Robert had child development specialists come to the house three days a week. But the search for anything that might switch on an inner light had just begun.

NATUROPATHIC REMEDIES TESTED

Sandra and Sergio tried naturopathic remedies, special vitamins, new soaps and new detergents. There was a steady stream of new diets that cut out dairy products and anything with red dye. A gluten-free regimen was particularly unpopular in the household and triggered months of dinner battles. Nothing helped.

“Oh, the money we spent,” says Sandra. “We did everything but swim with the dolphins.”

Without many guideposts from the medical community, looking for answers can be a quest in a black hole. In 2000, the Rosicas tried “auditory aerobics” — \$5,000 for two

Yet the move wasn’t smooth. For years, the Rosicas attended school events involving all the students while one or both of their sons were off to the side, not following anything. “It was almost as if they’d dissolve into the background,” says Sandra. “They didn’t know how to play as part of the group.” As Sandra’s eyes well up with tears at the memory, Sergio reaches over and gently takes his wife’s hand.

Raising one child with a learning disability is hard on any relationship. Two makes it even more stressful, and many couples see their marriage dissolve under such strain. The Rosicas hit their rough patches, too, at one point alternating between fights and stony silence. Sandra wrote her husband a letter saying that if he didn’t want to cope with the struggle, she wouldn’t hold him to it. He wrote back that he wanted to be on board and be a team.

Yet Team Rosica’s challenges continue. Since 2005, Sandra has faced multiple sclerosis, a neurological condition that attacks the central nervous system and often leaves its victims disabled. The disease is in remission,

Raising one child with a learning disability is hard on any relationship. Two makes it even more stressful

weeks of intense, twice-daily sessions using sound waves that try to stimulate the brain.

It sparked a breakthrough with Robert. Within weeks, he had gone from screaming and being unable to communicate to speaking clearly enough to be understood, a boon when he returned to preschool and celebrated his 4th birthday. But the therapy made no impact on Frank. A second session the following summer also produced no improvements.

“I don’t regret any of it,” says Sergio, who works for Calgary Transit, the city’s bus/light rail transit company. “In the back of your mind you always think, ‘This one will do it.’ You don’t know what’s going to help them. How can you not try?”

SKILLS TO LIVE INDEPENDENT LIVES

Like all parents, the Rosicas wanted to ensure that their boys had the tools to live independent adult lives. And that meant attending mainstream school. A bubbly woman with a ready smile, Sandra developed a tough skin battling for Frank and Robert. She fought and cajoled to get classroom aides who could provide structure for her sons in Calgary’s Catholic school system.

kept in check by daily medical injections, but instances of tingling in her arm are a stark reminder that she is facing too much pressure.

That pressure has built up through the years. When Sandra visited her sons’ classmates to explain autism and the actions that might make others uncomfortable, she was often peppered with questions that would open up a whole new realm of pain. Had she done something during her pregnancy to cause autism? Did she drink? Had she fallen? Had the baby fallen? And why would God do this?

“The kids would end up feeling sorry for me,” she says softly.

The journey has often been lonely. A cause for autism has yet to be discovered. In the 1940s, the medical community blamed it on bad parenting: “refrigerator mothers” whose uncaring style forced babies to retreat into themselves. Later, it was believed that childhood vaccines played a role, or the choice of food given to children. All of these suggestions have been debunked completely or questioned.

Music teacher Michelle Goyer marvels over the changes in Frank from the time she met

him at the beginning of Grade 4 to the end of Grade 9. In his later years at St. Gregory school, Frank made great strides. “In grade 4, kids tolerated him. By the time he was in grade 9, it was, ‘This is Frankie, this is who he is, and we like who he is.’”

FRANK PLAYS FIRST TRUMPET

Frank became “a presence” at the school. He played first trumpet with the concert band and did anything that needed to be done for whatever team or sport was playing on any day. His efforts were recognized with the Spirit Award, which is presented to a student who shows incredible caring and has realized his potential.

“It’s pretty inspiring to see a student who has autism rise above the ranks and succeed,” said Goyer, who presented Frank with the accolade. “Those kids gave him a standing ovation when he got that award. They saw the changes, too.”

Robert, now in Grade 8, has also made great strides. An honour student with a social personality, he has overcome outbursts and most of his repetitiveness issues. He interacts with his classmates and can make eye contact.

As the boys move through higher grades, aide hours have been cut back. They are down from as many as 30 hours a week in the early elementary years to 15 hours a week now for Robert and none for Frank, who is in high school. Frank’s marks are approaching the honour roll. He is on student council and plays trumpet in the school’s jazz ensemble and big band. He recently joined Junior Achievement, and for the first time, his parents didn’t mention his autism. While Frank can still be socially awkward and interrupt conversations, he is quick to apologize if his actions are pointed out.

A GOOD FUTURE

The mountain of effort that the Rosicas have made to help their boys has paid off. When the Rosicas look into the future, they see that Frank and Robert have a chance at regular lives — to live on their own, to have careers and families. Both boys are focused on finishing school and say they plan to go to university.

“When Frank was little, doctors said there wasn’t much hope,” said Sandra. “The best part is seeing the gains and knowing they have a future.”

I was fighting all these years for a diploma. I know now they will do something.” ●

Dyslexic student carves brilliant career

By Bethany Murray
FAMILY TIES STAFF WRITER

Every day, a quiet war damages the lives of as many as a billion people worldwide. All too often, the casualties are children. Robert Langston emerged from this war highly decorated and battle-hardened, then turned around to wage combat for others in his wake. Ill-equipped and ill-prepared men and women fight each day for the victories he has seen. The war is in education, and the battle is over dyslexia.

In the second grade, Langston scored an 84 on his I.Q. test. He graduated from high school functionally illiterate and from college with written language skills as low as the third-grade level. While this may sound impossible to some, it happened — and it happens all the time.

Langston is a soldier, and he is not alone. As many as 20 per cent of the world's population may have some symptoms of dyslexia. This means that, as of January 2010, approximately 1.4 billion people might suffer from slow or inaccurate reading, poor spelling, poor writing, word confusion and the impact these issues have on their lives.

Dyslexia is a learning disability that interferes with the brain's ability to translate written images into meaningful language, impairing reading, spelling and sometimes mathematical ability. The disability is often inherited. Individuals with dyslexia read at far lower levels than expected despite having normal or above-average intelligence. It varies so greatly from person to person that no two dyslexics are alike. Severity ranges from mild to profound.



Like all kids, Langston enjoyed parties.

As a dyslexic student in the early 1970s, Langston felt completely misunderstood and alone. “I remember my first-grade teacher handing out work sheets for us to complete,” he says. “Anxiety set in immediately. My stomach would ache, and my hands would sweat so profusely that I couldn’t even grip my pencil.”

He would spend the entire class period trying to see neighboring students’ papers, but even if he caught a glimpse, he couldn’t read well enough to steal their answers. At the end of the day, his work sheet would be blank. When his teacher would call for papers to be brought up by rows, he reverted to that most basic of human instincts — fight versus flight.

FIRST GRADE FEARS

As a first-grader, he chose flight. “When my row was called, I would slip to the back of the line and then the classroom,” he says. “I would hide, ironically, in the reading group area behind a dollhouse that had been converted into a bookcase.” He would sit looking through the small windows, folding his work sheet down into a paper football, watching for his row to return to their seats. “That year I went home with a lot of paper footballs in my pocket,” he says.

Langston’s dad, also a dyslexic, had grown up in the 1940s and ’50s, when not much was known about the disorder and even less was being said. “He is a living testament that it is possible to thrive with dyslexia, despite the imperfect public education system,” Langston says with deep respect. “My strong-willed mother refused to let her son suffer due to a learning disability. Together, my parents and I took on the U.S. public school system to fight for my right to a fair education.”

DETERMINED TO GO TO COLLEGE

As he progressed through school, Langston grew more and more determined to go to college and earn his degree. But he encountered several obstacles on that road. One of the first challenges was the general misconception of dyslexia.

When he scored the 84 on his I.Q. test in second grade, the school advised his mother to teach him a trade because he would never make it through high school, much less college. That day, his mom made a decision that would change his life. She thought, “My son is smart at home but failing at school, so there must be something wrong with school.” Challenging the school system’s rules was



Early on, Langston distinguished himself in sports.



Despite disability, he conquered as an outstanding student.

unheard of at the time, but she fought for the changes that would empower her son to learn, and in doing so, secured his future.

As they discovered how he learned best, they fought first to have him tested for dyslexia and then to have him taught via those methods in school. They enlisted the help of his teachers by showing them that, if they made reasonable adaptations, he could pass their tests. One by one, they established accommodations such as oral testing, untimed tests and taking tests in a separate, quiet classroom.

Langston began to tell his friends about his dyslexia. Friends, family and classmates began taking notes and reading to him. The girls he dated in high school joked, “Rob will take you out to a nice restaurant and pay for the

dinner, but you’re going have to read the menu to him.”

He was beginning to accept his dyslexia and was poised to earn his high school diploma when he encountered another roadblock: the SAT (Scholastic Aptitude Test).

To gain the special accommodations he needed in order to get college-worthy scores on the SAT, Langston and his parents presented years of documentation to the College Board, including public school and privately administered psycho-educational evaluations and re-evaluations; Woodcock-Johnson Tests of Achievement and Wechsler Adult Intelligence Scale scores; testimonials from family and friends; and handwritten letters from teachers testifying to Langston’s success in their classes with proper adjustments. The board approved a list of accommodations, and he scored high enough on the SAT to win admission to college — where he would fight his last major battles with dyslexia.

Still energized from the success of getting his high school diploma, Langston was ready for the adventure of college. But not everyone in college was ready for him.

“I went to great pains to find teachers who would work with me. My English 101 teacher was great. She graded me more for my content than spelling and punctuation,” he recalls. As a present to her, he wanted to turn in his last paper perfectly edited. “I approached another English professor at the school and asked if he would edit my paper, explaining that I was dyslexic. He not only refused to help me, but asked that I never take a class from him, because he felt that dyslexics were slow and lazy. He said, ‘I am not the teacher for you.’”

LANGSTON FIGHTS WAR OF IGNORANCE

Years of struggles with people like that had built Langston’s self-esteem to the point where this did not bother him. He recognized it for what it was — ignorance. He agreed that the man was “not the teacher for him” and found a more willing professor to help. He had bigger problems facing him than a misguided academic.

The state-mandated test in Georgia’s university system — the Regents’ Test — meant pass or fail for his educational career. Once again, he and his family enlisted the help of faculty and staff who had seen what he could do with the right support. Because of their efforts, the head of testing for the

Regents’ Test personally administered the exam with the established list of accommodations, and Langston survived to fight another day.

He enjoyed for several years quietly accumulating credits toward graduating with a degree in art and graphic design before facing his final hurdle: the dreaded foreign-language requirement. “Again, it was do-or-die time for my diploma. But by this point, my parents and I were learning that the range of our standard accommodations was falling short. I signed up for Spanish but drew a solid ‘F’ at midterm.” It was time for a whole new strategy.

Private testing by the notable Resource Educational Center in Atlanta resulted in recommendations that persuaded the university’s vice president and dean of facilities to approve an alternative class list for Langston’s foreign-language requirement. It consisted of mostly 300-level or higher history classes. At least they were in English.

Langston earned his college degree on Aug. 22, 1993. It had taken seven years, but he was successful. “I never would have made it without the efforts of my parents, who were steadfast in the belief that the system was flawed, not me,” he says. In turn, he now continues the battle on behalf of every child who feels inadequate because the school system doesn’t plan for varying methods of learning. “Dyslexic thinking can be a gift,” he says. “It shouldn’t be stigmatized — it should be cultivated. When it comes to dyslexia, we should change people’s minds, not their brains.” ●



Robert Langston is an award-winning advocate for learning-disabled children. He is the president of the Langston Company, Inc., and founder of For the Children Foundation. A distinguished speaker in the business community as a resource consultant to Vistage, an internationally elite organization of CEOs, Langston is a graduate of the University of West Georgia, a twice-published author. He is currently a dyslexia expert for Psychology Today, where he writes the blog The Power of Dyslexic Thinking. To learn more, please visit www.robertlangston.com.



Like all kids, children with learning disabilities thrive on parental love and support.

Advocate for your children

By **Gavin MacFadyen**
FOR FAMILY TIES

Gavin MacFadyen is Troy Media's legal columnist. He's written for the Calgary Herald, Edmonton Journal, The Globe and Mail and the Buffalo News.

The duty of government to provide education to all its citizens is the means through which our futures are cultivated and secured. No society could long survive a breakdown in its public-education delivery system. Any splintering of service, so that the opportunity for acquiring a basic skill-set was not assured, would sound the death knell for our way of life and shared futures.

The task facing parents is to ensure that their children are maximizing potential. This is not a quixotic quest. It is an obligatory pathway to the work force. But imagine the child has an impediment,

an extra burden that goes far beyond the transient rebellions of growing up.

The anxiety felt by parents of children with learning disabilities is understandably acute. The stakes are nothing less than whether their child will be able to attain the self-sufficiency and personal fulfillment that come with earning a living and acquiring the self-respect to which every citizen is entitled to aspire.

SO WHAT'S A LEARNING DISABILITY?

Let's be clear about what we mean by learning disability.

This is how the Learning Disabilities Association of Canada begins its comprehensive definition:

"Learning Disabilities' refer to a number of disorders which may affect the acquisition, organization, retention, understanding or use of verbal or nonverbal information...as such, learning disabilities are distinct from global intellectual deficiency."

This is legalspeak trying its best to be sensitive in emphasizing that there is an underlying neurological, chemical or cognitive impairment affecting a child that goes beyond the natural differences in intelligence and ability found among the average population or the condition of being so severely mentally compromised that one can't function in any setting.

Here is where parents are obliged to act. Don't leave it up to the school to tell you whether your child has a learning disability. You know your child best; you observe your child most. As dedicated as the vast majority of educators are, they don't have the time or the resources to be as personally invested as you are in your child's future.

KNOW YOUR RIGHTS

Parents need to know their rights and the school's responsibilities. Most important, it is the parents' right to be an active participant in the construction of a suitable learning plan that addresses their child's unique challenges in coping with and adapting to the specific condition affecting his or her ability to acquire, process and apply information in the classroom. It is the school's responsibility to facilitate this process and respond and modify programs that aren't meeting the child's needs.

If you begin with the notion that everyone involved wants to help but may not know exactly the best course of action, you can treat the beginning stages of placing your child in an appropriate learning environment

as a team effort where it has become your job to take the lead. Parents must become effective, informed advocates.

Every jurisdiction has subtle differences, but there is a rather uniform structure and procedure that can be learned, adapted for and applied to a specific district or community, wherever that may be.

First, know that it is the legal obligation of the school board to provide a suitable education for all students. It is the board's further obligation to provide testing and

assessment of a student with a suspected learning disability, in consultation with the parents. If the school refuses to do so, then it is every parent's right to insist on it.

If the refusal continues, the parents should tell the school and the board they intend to secure the assessment independently and to send the school and the board the bill.

Once your child has been recognized as having a learning disability, an (IEP) Independent Education Plan will be drawn up in consultation with a Special Education

Don't leave it up to the school to tell you whether your child has a learning disability. You know your child best



Parents must monitor school system so it's meeting their LD children's needs.



Committee of which the parent is a member. That is critical. It is your ongoing right to insist on changes, adaptations and accommodations to this plan if it becomes clear that your child's unique and special needs aren't being met.

PARENTS SADDLED WITH HEAVY BURDEN

This places a heavy burden on parents who are already far too busy with trying to put food on the table. But it is necessary if the child is to receive the directed and effective instruction that will allow him or her to flourish. Too often, challenged school boards will take the path of least resistance and be more concerned with order and efficiency than with opportunity and enrichment.

If the school digs its heels in, then it is the parents' statutory right to appeal to what is usually a specialized arm of the school board. It is at this point that you may want to consult a special-education lawyer who can present your child's case with supporting medical and academic studies related to the child's specific condition.

NO MAGIC BULLETS

Unfortunately, there are no magic bullets. The child will have a lifelong set of challenges to master and overcome. The onus is squarely on the parents to remain vigilant, assertive, informed and, above all, engaged in the everyday education being provided to their learning-disabled child.

Teaching learning-disabled children is a challenge for educators as well, but we must never forget that the success these young people will enjoy when they are able to integrate fully into future workplaces will be a victory not just for them, but also for all of us. ●



There is no shortage of educational options for children with learning disabilities.

Get support from your school

Parents who suspect their child has a learning disability would be wise to consult with the classroom teacher.

If the teacher does not make a recommendation to the principal that the school put a review of the child's needs in place, parents can initiate the process themselves. Although the specifics might vary from province to territory, every Canadian educational authority has a formalized process of determining and ensuring a student's right to special educational support.

In Ontario, an official flagging by principal or parent results in the student's referral to an Identification, Placement and Review Committee. The IPRC is responsible for determining whether the student is exceptional — that is, whether the student's "behavioural, communicational, intellectual, physical or multiple exceptionalities are such that he is considered to need placement in a special education program" (SPECIAL EDUCATION: A GUIDE FOR EDUCATORS [HTTP://WWW.EDU.GOV.ON.CA/ENG/GENERAL/ELEMSEC/SPECED/GUIDE/SPECEDHANDBOOKE.PDF](http://www.edu.gov.on.ca/eng/general/elemsec/speced/guide/specedhandbooke.pdf), P. 209).

If a determination of exceptionality is made (including that of giftedness), the IPRC will choose the appropriate placement for the student. That placement might be resource support in the regular classroom; withdrawal from the regular classroom for less than 50 per cent of the day; integration into the regular classroom for a maximum of 50 per cent of the day; or full-day placement in a "self-contained classroom" with a special-education teacher. In cases where the student's needs are greater than can be supported by the regular school system (e.g., a student who is vision or hearing impaired, or who has profound learning disabilities or severe ADHD), a referral is made to a residential Provincial Demonstration School.

The terms of the student's special-education placement are laid out in the student's Individual Education Plan. The IEP must list educational expectations specific to the student; the services to which the student is entitled; and the methods and timeline for reviewing the student's progress. The IEP should be updated once every reporting period, or more often if warranted by the student's progress or failure to progress. Parents can find more information about the Ontario IPRC process (<http://www.edu.gov.on.ca/eng/general/elemsec/speced/identifi.html>) and the IEP process ([HTTP://WWW.EDU.GOV.ON.CA/ENG/GENERAL/ELEMSEC/SPECED/IEP/IEP.HTML](http://www.edu.gov.on.ca/eng/general/elemsec/speced/iep/iep.html)) on the Ministry of Education's website.

By Diane L. Duff

FOR FAMILY TIES

Diane L. Duff is the director of educational consulting firm Aldridge-Duff, which provides a host of educational services, including tutoring, mentoring, academic assessment, and reading remediation for students with dyslexia and reading disabilities. It has offices in Ottawa and Toronto.

OPTIONS FOR ONTARIO PARENTS

- Parents are entitled to attend all IPRC meetings, including decision-making and appeal meetings, and to be represented or accompanied by an advocate.
- Prior to IPRC meetings taking place, parents should study all documents the committee will consider in making its recommendations, including the results of any academic assessment performed by the school's special educational personnel and any medical and psychological reports.
- Parents may be asked, prior to or during the initial IPRC meeting, to consent, in writing, to the psycho-educational assessment of their child (a student 16 or older must provide his or her own informed consent). The school does not have to obtain parental consent to perform an academic assessment. (See next page for the difference between the two types of assessment.)
- Parents are entitled to opt for a private assessment (and to decide whether they want to disclose the results to the school authority). A list of licensed psychologists who conduct psycho-educational assessments can be found through the provincial College of Psychologists. Family physicians also can provide names and make referrals.
- Parents are entitled to take their time considering the IPRC's recommendations. Many advocates suggest that parents not sign the document until they have had time to reflect on the services being offered to their child. Parents have 30 days to return the signed document to the IPRC.
- Although the IPRC recommendations are made in consultation with parents, the committee is not bound by the parents' suggestions.
- Parents who disagree with the IPRC's placement decision should not sign any documents, and should carefully observe procedural and time guidelines about how to initiate an appeal.
- The IPRC automatically conducts an annual review of each student's case, but parents may request a review IPRC meeting after their child has been in a special education program for three months.

FIND OUT IF YOUR CHILD HAS A LEARNING DISABILITY

Here is how to find out:

- **Academic Assessment.** The purpose of academic assessments is to determine how much students have learned. Academic assessments use standardized criteria to measure student performance in various subjects, and can also include measures of general information processing.
- **Psycho-Educational Assessment** (also referred to as psychometric assessment). For the purposes of diagnosing a learning disability, psycho-educational assessments are comprehensive. They include measures of intellectual ability, memory function, visual-perceptual skills, and social/emotional functioning. They may also include rating scales for attentional difficulties. Psycho-educational assessments are conducted by registered psychologists who work for school boards or who are in private practice.
- **Online tutoring:** Tutors work with students using a drawing-board web application or in a virtual classroom setting. Typically, there is no set lesson schedule. As a result, when students log on, they have no guarantee of working with the same tutor every time. Self-directed students who need occasional subject-specific support probably reap the most benefit from this type of tutoring.
- **One-on-one tutoring** (on-site or in-home, provided by private individuals or tutoring agencies): Tutors provide regularly scheduled, individualized support. One tutor is usually assigned to a student for a term or school year. Tutors may not be certified teachers, and parents should be careful to distinguish between certified tutors, professional tutors, and certified teachers. One-on-one tutoring with a certified teacher—especially one who has experience working with students with

ability to work independently.

special needs — is often the best support for children whose needs are not being met through the IPRC placement or who struggle in the absence of a “special needs” designation.

- **Cost of tutoring.** Parents must pay for tutoring themselves. Fees vary from one private tutor to the next or one agency to the next.

FEDERAL GOVERNMENT SUPPORT FOR PARENTS OF LD CHILDREN

- Parents may apply for the Child Disability Benefit (CDB), which provides a maximum of \$2,455 per year (calculated by family income) to families with a child under 18 who has “severe and prolonged impairment in physical or mental functions.” [HTTP://WWW.CRA-ARC.GC.CA/BNFTS/FQ/CDB-ENG.HTML#Q1](http://www.cra-arc.gc.ca/bnfts/fq/cdb-eng.html#Q1)
- Parents may claim a Medical Expense Tax Credit (METC) for tutoring when a child has been diagnosed with a learning disability and when the diagnosing practitioner recommends support in addition to what can be provided by the school. Parents in some provinces and territories may claim a tax credit toward some of the services provided by a psychologist, speech pathologist, or occupational therapist. [HTTP://WWW.CRA-ARC.GC.CA/E/PUB/TP/T519R2-CONSOLID/README.HTML](http://www.cra-arc.gc.ca/e/pub/tp/t519r2-consolid/readme.html)

Every Canadian educational authority has formalized a process of determining and ensuring a student's right to special educational support.”

- **Additional support for students.** When the services provided through the IPRC placement are insufficient to help students keep up with the academic demands of school, or when students struggle in the absence of in-school support, many parents look for outside help.
- **Free support.** Sources of free support include volunteer tutors in the community; help from friends who are subject-matter experts; and classroom teachers who have time available after school or at lunchtime. Parents also should ask their child's teacher about the Tutors in the Classroom programme, which brings post-secondary students into classrooms to help students with math and literacy skills (funded jointly by school boards and The Literacy and Numeracy Secretariat of Ontario).
- **Fee-for-service tutoring.** Group tutoring (especially in franchised or chain businesses): A tutor sits with a group of students — usually no more than three — each of whom is working on different material at a different grade level. The format is said to encourage the student's



SOURCES OF FINANCIAL SUPPORT FOR PRIVATE PSYCHO-EDUCATIONAL ASSESSMENTS

- Mental Health Centres, Teaching Hospitals or Hospitals with Mental Health Programmes: These institutions may provide psycho-educational assessments under Ontario's provincial health plan (OHIP) if the child's needs include behavioural or emotional issues.
- Private medical insurance: Some private insurers and group plans will defray a portion of the cost of a psychological assessment if a referral is made by a medical doctor.

To learn more about Aldridge-Duff, visit <http://www.educationservices.ca/> or call (613) 730-7096; or (888) 636-7741 (Canada only); email: aldridge@bellnet.ca

Information and additional resources

AUTISM SPECTRUM DISORDERS

AN ALBERTA FAMILY'S STRUGGLE WITH AUTISM
(JUDY MONCHUK)

Autism spectrum disorders (ASDs) are a group of developmental disabilities that affect the way the brain handles information. They manifest differently in each person and can range from mild to severe. The cause or causes of ASDs are unknown.

Similar symptoms shared by people with ASDs include social, communication and behavioral problems. They could repeat certain behaviors and be resistant to change in their daily routine. Their thinking and learning abilities vary from gifted to severely challenged. It's common for people with ASDs to have different ways of learning, paying attention or reacting.

There are three types of ASDs:

1. **Autistic disorder:** involves significant language delays, social and communication challenges, unusual behaviors and interests, and sometimes intellectual disability.
2. **Asperger syndrome:** involves social challenges and unusual behaviors and interests, but usually no problems with language or intellectual ability.
3. **Pervasive developmental disorder — not otherwise specified (PPD-NOS):** These people meet some, but not all, criteria for either autistic disorder or Asperger syndrome. Symptoms might only result in social and communication challenges.

Coping With Autism

One in 165 Canadian children has an autism spectrum disorder, affecting how he or she communicates with others. The quirks or outbursts of an autistic child can be hard for family members and even strangers to handle. But the most difficult thing for parents can be the negative reactions they receive from people who are frightened or annoyed by the children's actions.

Here are some tips compiled by parents and caregivers that can help bystanders make situations less frustrating:

- **Control tantrums.** While any child can have an emotional outburst in public, autistic tantrums can be more intense. Getting control of an autistic child can be difficult. Strangers can help by not staring with disapproval or berating the parent or child for not being in control.
- **Set boundaries.** Autistic children have problems knowing the boundaries of acceptable behavior. This can mean they say things that may be considered rude or thoughtless. Before reprimanding the child, watch for the reaction of their caregiver and take a cue from those actions. If the child apologizes, accept the apology gracefully.
- **Be prepared for odd behavior.** Autistic children can act in ways that others consider strange. They may make guttural sounds, look off in the distance, twirl items repeatedly, yell or scream. As hard as it sounds, don't stare or draw attention to the odd actions. If possible, offer a smile to the parent or caregiver.



Advice from Temple Grandin

Temple Grandin, an autistic woman whose life was recently detailed in an HBO movie, has inspired many parents of autistic children. A best-selling author and a top scientist who works with the livestock industry, Grandin is known for her advocacy work, which includes teaching tips for those with autism. Here are four:

1. **Good teachers are critical.** Grandin was 2 ½ when she began attending a structured nursery school with firm teachers. She was taught manners at an early age and was expected to behave. The combination of school, speech therapy and play sessions kept her brain connected to the world.
2. **Accept different ways of thinking.** Grandin thinks in pictures, not words. Many people with autism are visual thinkers who learn better with picture flashcards of things that can be used to demonstrate actions.
3. **Avoid detailed verbal directions.** People with autism have a hard time remembering sequences or directions with more than three steps. If the child or adult can read, write down instructions.
4. **Computers help.** Many autistic people have problems with fine motor control, which can be very frustrating for a child expected to write. Typing on a computer is often faster and easier.

Internet information sources: www.beliefnet.com; <http://www.autismuk.com/index6sub.htm#pdd>; <http://www.iidc.indiana.edu/IRCA/TempleGrandin/TeachingTips.html>

TIPS FOR PARENTS OF DYSLEXIC STUDENTS

DYSLEXIC STUDENT CARVES BRILLIANT CAREER
(BETHANY MURRAY)

1. **Champion education.** Don't assume that a teacher is well-versed in learning disorders. Help educators understand how your child learns best and be active agents in your child's schooling. Volunteer at the school. Attend PTA meetings. Be your child's educational advocate.
2. **Encourage, encourage, encourage.** Your child may endure harassment and embarrassment because of his learning challenges. Remind your child daily of your support and help her see the many things she does well.
3. **Provide accommodations.** Oral testing, untimed tests and working in a separate classroom were some methods that helped Langston succeed. There are many more, including some great technological aids. Do your research and figure out the combination that works for your child.