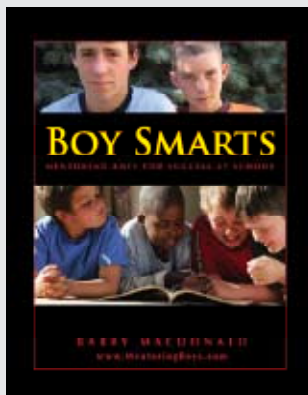


NAVIGATING DIAGNOSIS:

*Parent Detectives
in the World of
Educational Experts*



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THE September Newsletter *Youngest in Kindergarten More Likely to be Diagnosed with ADHD* generated much stimulating feedback, including a front-page *Vancouver Sun* article. Most people who wrote offered their personal story or expertise, cautioned against quick expedient diagnoses, and advocated for a well-rounded consideration of a children's broader needs, not simply an 'attention problem'. One passionate Surrey teacher wrote:

"Even before I allow myself to consider the possibility of an attention problem, I ensure that I have a positive relationship with a student so that he will reveal to me, either directly or indirectly, his learning preferences, learning struggles, learning passions, and anything that will help me to respond more effectively to him. I also make absolutely certain that I take time to talk with a parent about what has worked in the past with their child as well elicit suggestions that can guide my practice."

Another teacher, who identified herself as 'Cathy G. from Ontario,' wrote: "I am as guilty as so many others in my profession of wanting to have a label to make sense of students we struggle with. Sometimes it gives us very prescriptive ways of working with them that we hadn't considered. Other times it can be

very limiting and frustrating. I have had many situations with students where I just knew we were missing something important. I recall one particular Grade 4 student, “B”, who would often stare into space for long periods of time and then shake his head as he came back to us. He had huge gaps in his knowledge and skills, but since he was a quiet boy, he had slipped through the cracks and was barely meeting expectations. Since it was a small community and the parents themselves had gone through the system diagnosed with learning disabilities, it was assumed that “B” had the same issues. A colleague suggested ADD. However, my intuition told me something else was going on. I began searching and read about petite-mal seizures so I spoke to his mother. It took several brain scans, but the final one showed that “B” had a serious seizure condition which had the potential to develop into grand-mal seizures.”

While many writers shared their uneasiness about stimulant medications, others reported that medication was moderately effective for their child. Interestingly, a medical doctor who cautioned about the overuse of drugs to solve common childhood behaviour problems quoted from Dr. William Glasser’s book, *Warning: Psychiatry Can Be Hazardous to Your Health*: “It is curious that, in an era deluged with an avalanche of new statistics detailing the pervasiveness of childhood poverty, neglect, and abuse, the psychiatric profession has chosen to ignore the obvious psychosocial causes of most childhood behavioral disorders and has opted, instead, to crusade for the wholesale drugging of this involuntary population on the basis of totally unsubstantiated theories of biological causation...



Ritalin is only confirming what many psychiatrists and pediatricians already believe: that it’s better to apply their prestige and clout in the community to the real problem: improving our schools so that students find them enjoyable enough to pay attention and learn in an environment where drugs are not needed.”

Another family doctor in my local community commented to me at the gym early this morning: “Diagnosing ADHD basically depends on where you live in the world. You don’t see many children diagnosed with ADHD in China, or in Africa where I spent several years working as a physician.”

Understanding that the checklist medical doctors and psychologists use to diagnose ADHD is highly subjective, one parent pointed out that ADHD is not like a broken leg or a bacterial infection. Her story shows how much a diagnosis is influenced by the attitudes of adults toward high-spirited and impulsive children: “In Grade 1 the teachers were distressed by my son’s activity level and his indifference to conforming. His printing was rushed and

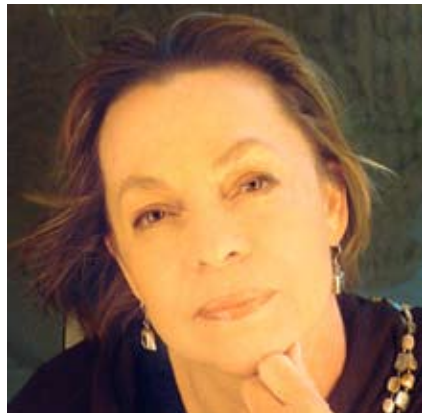
messy and he fell out of his desk at least once every day. They spoke to us of attention deficits, immaturity and focus problems, suggesting that we have him evaluated...He struggled until Grade 3, his turn-around year. His teacher had a knack for working with individual learning styles and insisted that we have Kevin assessed,

not for ADHD, but for giftedness. It took the whole school year before Kevin got his evaluation; he tested at least 3 full grade levels higher on math, science and reasoning. He wasn’t distracted. He was seeking stimulation.”

If we leave for now the politics surrounding

medication, we can find consensus among most professionals that the best treatments for ADHD include exercise, nutrition, restful sleep, stress management, and lots of loving encouragement.

Karen Elkins, a Vancouver parent to a son who was diagnosed with ADHD during his early years, now consults with parents of children with unique educational needs. She indicates that in her practice as a parent consultant and advocate, she spends a lot of time with parents to ensure that she fully understands a child's likes, dislikes, and way of experiencing the world. In particular, Karen carefully reads Ed-Psych Reports with parents, helping them make sense of unfamiliar language. I began my interview with Karen by



asking why parents would bring an Ed-Psych Report to her, as it is the responsibility of the examiner to fully explain findings and recommendations.

Q: “It seems strange that parents would consult with you, a person outside of the school system, a person who is not a classroom teacher or a school psychologist. I thought these reports were to be discussed with professionals at school, where recommendations would be carefully explored. Why would parents seek the guidance of an external parent advocate and consultant?”

A: “I should first clarify that most parents are probably satisfied with school-based discussion about their child's Ed-Psych Report. I get to meet the parents who are dissatisfied. These parents question both the report findings and their recommendations. Often, these parents report to me that they feel overwhelmed by the details reported at these meetings. I recall early on with my own

struggle to make sense of educational jargon and percentile rankings that were bandied about at my son's Ed-Psych Report meeting. I dearly wanted to advocate for him but lacked the language and knowledge of what to look for, or how to speak up. So, I made a ten year project of meeting with Vancouver experts to better understand the different profiles children typically present, as well as those profiles that can sometimes confound the experts. Later, after my son was diagnosed as gifted, I became the Vancouver coordinator for the Gifted Association of British Columbia and ran five international conferences. I also ran Silbury, an education and resource centre for the gifted for five years. Mostly, parents consult with me to

make sense of their child's Ed-Psych Report and to discuss recommendations in a non-threatening way. Together, we become parent detectives in the world of educational experts.”

Q: “Finding out that your child might be learning-disabled or gifted, or both, can be daunting. What have you discovered over years of meeting with parents and discussing their child's learning needs and the Ed-Psych Reports?”

A: “The parents who come to me are frustrated and want me to comb through their child's Ed-Psych Report to help them highlight and understand the big ideas. But mostly, they want to know what they can do to help their child learn and be happy. Sometimes I notice important details in the assessment that seem to be missed in the summary, or I notice that the report recommendations appear hasty, dated or even incomplete.”

Q: “To complete a proper diagnosis for a learning disability, ADHD, or any mental health issue, professionals need to first rule out other possible causes for the behaviours at issue. Has this been your experience? What have you noticed?”

A: “You are correct. Before drawing any conclusions, experts must first rule out vision, hearing, sensory, mood, nutritional, and school or home situational complications. This process is called a ‘differential diagnosis.’ In an ideal world, professionals would follow a procedure to gather history, tests, and all pertinent details to guide them to the best possible diagnosis. With ADHD using a simple 20 question form is not considered best practice in making a diagnosis, nor does having a teacher and parent complete a *Connor’s* rating scale and then comparing their subjective views form an ADHD diagnosis. Experts are obligated to search farther afield and to more fully understand a child’s needs.”

Q: “I have received several questions from professionals challenging your comment in the last newsletter: “Sadly, once kids get labelled this way, it’s often very difficult to get them un-labelled.” What did you mean by this comment?”

A: “There is no process for ‘un-labelling’ a child. What I meant is that once people view a child in a particular light, the label can stick like glue. My worry is that children become objectified and their individuality melts

away. Kids become case studies and their complicated life stories become collected as statistics. While I agree that our western approach to diagnosis deserves some credit, it can also be highly limiting, and force us to view a child’s genius through a prescribed lens, rather than through a lens that is

open to what’s possible. I guess I am also concerned that children cry out through their behaviour and we don’t listen. Yes, we need to work with the best western diagnostic systems we’ve got, but we also need to hold space for creative forces to take the time to see each child as unique.”

Q: “I appreciate that your comments pertain to parents who believe their child’s difficulties are still misunderstood even after a discussion of the Ed-Psych Report or parents who are frustrated with incomplete follow through on the report’s recommendations. What have these parents taught you?”

A: “When adults jump to the assumption that ADHD is likely, many other symptoms fly out the window and become overlooked, especially visual or auditory problems. I’ve discovered far too many times that children with visual weaknesses will use verbal reasoning to talk their way through visual tasks. Such compensation strategies cover up their difficulties temporarily, but they do not resolve their problem. In my modest experience experts pay lip-service to auditory and vision problems in children.

I have yet to see anyone recommend vision or auditory therapy, even when the Ed-Psych Report reveals this to be an area of concern. Many don’t even recognize the difference between an Optometrist and a Developmental Optometrist, who specializes in diagnosing childhood vision problems and has particular training to improve visual

function so children can blossom academically. I recall referring one parent to a Developmental Optometrist; although her son had been cleared for vision problems in a doctor’s office, she later discovered through the Developmental Optometrist that her child was seeing double and couldn’t even track

BOYS are at greater risk than girls for most of the major learning and developmental disorders – as much as 4 times more likely to suffer from attention deficit disorder, dyslexia, and other learning disabilities. **BOYS** are at greater risk than girls for most of the major learning and developmental disorders – as much as 4 times more likely to suffer from attention deficit disorder, dyslexia, and other learning disabilities. **BOYS** are at greater risk than girls for most of the major learning and developmental disorders – as much as 4 times more likely to suffer from attention deficit disorder, dyslexia, and other learning disabilities.

for reading. I suspected this was a potential problem when I read in the Ed-Psych Report that the visual processing speed was exceptionally slow, yet this concern was never highlighted in the summary, or in the recommendations.

Hearing tests are often the same. Many children hear just fine but some struggle with processing what they hear. I know that you have addressed this in a chapter in your new *Boys on Target* book so I won't elaborate here. If the report or comments from the teacher reveal an auditory processing problem, I refer these parents on to see a Certified Audiologist for an Auditory Processing Disorder assessment. My preference is for parents to see an Audiologist who is also a Registered Speech-Language Pathologist, as they seem to have a better track record with diagnosing these problems in children.

Q: “We know that visual-motor weaknesses are common in boys with learning difficulties and those who are gifted. What have you noticed?”

A: “Absolutely. These difficulties may appear as clumsiness, lack of coordination, poor balance, poor pencil grip, slow handwriting speed, inability to cross the midline of the body without switching hands, difficulty cutting or drawing simple figures, and avoidance of motor tasks. When parents or teachers see any of these difficulties, it is important for the child to be assessed as early as possible. We know that an early program of remediation exercises is likely to prevent problems with underachievement down the road.

During my son's early schooling years I was shocked by how he knew everything about airplanes, but was unable to transfer his exceptional memory

and passion for learning to basic math computation or written output in the classroom. Many families approach me with similar quandaries and frustrations. As I talked with my son's teacher years ago, I learned that she too was just as lost as me. Most teachers do not learn how to read Ed-Psych Reports. I've also discovered that most principals don't know how to make sense of them either. This is not their job as educators.

With the exception of a school psychologist, very few people in the school system know what to do with results from an Ed-Psych Report or how to generate recommendations that will make real change in a child's life. I have also found that so many of the recommendations are limited in that they don't deal with root causes.



Q: “You are a parent and consultant on the leading edge of advocacy for children who slip through educational cracks. From my own experience as a BCTF representative on a taskforce that developed the first **Parents as Partners Leadership Training Module** in the late 1980's, I learned that children benefit when we pull together our differing talents and capabilities as parents, teachers, school psychologists, and health-care providers to help children grow and flourish. Back then it was considered inflammatory for parents to have a real say in the power structures of the school—for example, having input into School Board of Trustees' decision about who they might hire as the next superintendent of schools, but now such practices are commonplace. In this same light, we are now becoming more comfortable with the notion that educational experts do not have all the answers. While some experts with eight or more years of university education might be

threatened by your practical know-how as a parent advocate, you are cautious to respect their training while also holding them accountable. Is there anything else that you would like parents to know?”

A: “When children struggle with learning we should be looking for coding and decoding issues, processing speed, and working memory with something as simple as digit spans. Realize that exceptionally smart children can present as not so smart when they have slow processing speeds. These are the kids who daydream excessively or become the class clown. When these children struggle with tracking instructions, they become overwhelmed in classrooms where the teacher gives a lot of verbal instructions—that is, talks too much. The more a teacher can make learning real with hands-on activity and visual cuing, the more they will be able to activate the right hemispheres of kids’ brains. Many children also need remediation to increase their processing speed so they can more easily transfer information from the right hemisphere to the left hemisphere.

We have to take a wider understanding of learning problems to consider everything. How do a child’s senses, eyes, ears, touch, and neural pathways take in information? We have to carefully consider the food children ingest, the atmosphere, the prevailing emotions around them. Too often we rush in with tutoring or drugs, when kids are crying out for us to take the time to watch, listen, and truly understand them. Too often we set in motion a sense of inadequacy for the child that becomes their life story. Years ago my son retreated into solitude. The playground bullies met him at every passage. Thankfully, today is different for him. Today he is an engaged and active teenage boy who has a passion for strategic video gaming and insists on arguing the merits of gaming with me. For me the important thing is that he is asking critical

questions about life and he is engaged. Kids blossom when they are personally invested in what they are learning.”

Thank you Karen. I appreciate your candor and willingness to speak up on behalf of frustrated parents and children you have worked with. Undiagnosed learning difficulties are one of the most underestimated causes of failure in both school and life. I admire your courage to venture into the expert world of the DSM diagnosis as well as your manner of gently challenging limiting views where they exist while also respecting the prevailing professional wisdom.



Before the discovery of neuroplasticity, helping children with learning disabilities was based on the premise that deficits could not be strengthened, only worked around or compensated for. Those with trouble listening and taking notes were encouraged to tape record lessons or obtain classroom notes from other students. Even up through the 1980s, medical schools taught that the brain cannot recover from deficits or regenerate itself. Today we know differently.

We know that the brain can change its structure with stimulation. Recall that just ten years ago Dr. Eric Kandel received the Nobel prize for showing us that as snails learned, the branches between their neurons were physically altered and enhanced.

Neuroscientists have since shown us that after amputation, the area of the brain that mapped or represented the lost limb gets taken over to be used to map adjacent areas of the body. Thus the brain can reorganize itself structurally. All these findings show the brain has more capacity to recover from deficits than once thought.

Children who struggle with learning or emotional difficulties need us to believe in their brain's capacity to change. They also need us to be mindful of our own subjective biases as we help them build their confidence to learn. •••

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Karen Elkins is an independent consultant who has been a guest on the Bill Good Show along with international experts like as Dr. Linda Silverman and Dr. Thomas West. She has also been interviewed on television and radio (CBC, CKNW, CHMB, Conscious Living Radio, and It Takes a Village Co-Op) and has been featured in The Vancouver Sun, The Province, Shared Vision Magazine, The Vancouver Courier, and North Shore News.

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