

ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD) FROM THE INSIDE OUT

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EDITOR'S NOTE: The following article takes the form of a letter to the field from a parent who is also an expert in the field of learning disabilities.

Dear child and youth care workers:

I am a professor in a Canadian university and the mother of two teenage boys who both have Attention Deficit Hyperactivity Disorder ("ADHD") coupled with learning disabilities ("LDs"). My sons are now in private high schools, one son a junior and the other a senior. I write to you now in this open public letter as the parent of two special needs kids who, by all accounts, are considered high risk for school drop-out and psycho-emotional difficulties. My children were adopted at birth and I, like a large part of the general population, had never heard about ADHD and knew almost nothing about LDs. My husband and I were just thrilled to be parents and, in the early years of our children's lives, there was nothing unusual in their development that would have led us to suspect that they would each, by the time they were age five, be diagnosed with ADHD and fine motor difficulties. (One of my sons also suffers from a language processing difficulty, which was discovered as a result of further testing in his teens.)

You may be asking yourselves about the purpose of this letter, or about my intentions in writing it. Even more, you may be wondering why I have chosen to write to *you*. My reasons are twofold. First, I want to share with you what it means in concrete terms to parent kids with ADHD. Second, I want to tell you how, from my perspective, I see your role, particularly in academic settings, and to enlist your help by highlighting the many ways in which I think you can intervene effectively in the school context and make a significant difference in affecting, positively, the academic success and quality of life of these kids and therefore that of their families.

On being a parent of children with ADHD

It has been said that having one ADHD child is akin to having five "normal" kids. As a working mother, most of the little free time I have is spent guiding the family raft through varying waters, often tricky, rough or even stormy. Steering a clear course is a daily challenge that can be exhausting and sometimes overwhelming. I am tired most of the time.

When I read about the high rate of divorces in families where there are kids with ADHD, I am saddened but not surprised. Unfortunately, there are seldom if ever any "time outs" or time off when you are the parent of ADHD youths. When I come home from work, I am typically "on call" way past the usual bedtime of high school kids. I usually come home and check for mishaps; for instance, the tutor came but my son forgot to show up or, in the dead of winter, he left his boots at school. Or I may find that the medication that my younger son is supposed to take in the morning is still on the table where I left it. This can only mean that his hyperactivity controlled his day and most likely that of his teachers. I then proceed to check agendas and/or the Internet for homework assignments, specifically the parent/ teacher communication section, breathing a sigh of relief if I see a blank. More times than I care to remember, there is a note from a teacher that work is incomplete, late or missing, not to mention the innumerable telephone messages reporting inappropriate behaviour, detentions or visits to the principal's office. Last year, there was hardly a day that went by without the arrival of some unpleasant missive.

Reading this thus far, you might feel that what I have only briefly sketched is not unlike the daily routines of many parents. I am well aware that all families have their ups and downs, and that there are days and periods that are tougher than others. Parenting is arduous work, and mothering two teenagers is reaching inside oneself to love and support at a time when the necessary counter dependence that teens go through makes them so unlovable. But parenting two kids with ADHD is being on call all the time, like wearing a beeper that never gets shut off or hosing down fires all too frequently. In the late afternoon, calling home from work is never just a routine check-in, but rather an exercise in holding one's breath, praying for no bad news and then, if I am lucky, sighing with relief that I might get through the day without any incidents. There are days when I would rather drive around the block countless times than go home, and then when I do, I inevitably feel besieged and bone tired.

Being the parent of two teens with ADHD and other LDs means that when I think about my kids and the people with whom they interact, I never make straightforward assumptions or entertain normal expectations about attitudes, actions or behaviour. I can't ever afford to take simple daily routines or tasks for granted. A homework assignment can remain buried for weeks in a school bag, forgotten until a call home from the school saying that the assignment is hopelessly overdue or that the last ten assignments have just not been done.

I am on my guard and tense whenever there is a social outing involving other parents with kids. Will I be able to relax and spend an evening without incident? You may be thinking that I am just an overwrought and anxious person by nature, but then you have not lived through countless gatherings where well meaning relatives suggest any number of approaches or remedies which are intended to transform my sons into "normal" beings and myself into a more satisfactory mother. When a new

friend is invited over, I wonder whether this will be his first and last visit and whether either of my sons will be invited back. I understand this, but I am also very sad. I feel protective of my boys, while at the same time feeling frustrated and irritated by them. Unlike most other youth their age, my sons, ignored by their peers, are not out with friends but are alone, isolated, and, I suspect, lonely, and certainly dependent on my husband and me for stimulation, entertainment and company. Though I want them to develop into autonomous young adults, I worry endlessly that they are ill equipped to do so and that, somehow, it must be my fault.

The sense of self-blame is not created in a vacuum. It is born out of a sense of being different and imposing difference on other parents, misguided school administrators, and well meaning and sometimes not so well meaning teachers and school personnel who view my sons' difference as a problem and an unwelcome reality in their classrooms. Difference becomes shame, and shame brings about blame. How many times have I struggled against my own defensiveness when I suspect my parenting skills are being questioned because a note has come home complaining that my son didn't eat any lunch because I didn't send any, or that yet again, pencils could not be found in his bag and had to be borrowed. I have thrown out more uneaten lunches than I can count because the Ritalin he takes also suppresses his appetite and I regularly send bundles of pencils to school for him which seem to evaporate. The fact that I am indeed doing my best never seems to be quite enough because one or other of my sons didn't write neatly, used a red pen instead of the required blue (and received a big fat zero on an otherwise satisfactory quiz as an incentive to obey the rules for quiz-taking in the future) (Is the "incentive" meant for me, to teach me a lesson? I wonder) or failed to write a book summary of at least three full pages.

The tragedy, of course, lies in all the positive aspects which don't get noticed, acknowledged or applauded. When you are busy navigating the rough waters of raising two youths with ADHD, you come to see only rough waters. You find yourself focusing on their problems and weaknesses, and these come to define your children. They become those problems instead of, as in my case, two fun-loving adolescents who are good, kind-hearted boys, with talents, skills and competencies that are more often than not eclipsed by the manifestations of their ADHD. Their disorder and its adverse impact in the school and social arenas eat into the fabric of positive family interactions and tend to take over family life, producing a whole new set of problems and negative interactions which are incredibly damaging to all concerned.

About Schools

For a child, the social institutions of family and school are the primary sites in the continuous construction of his/her sense of self. It is within these institutions, and in the way in which each impacts the other, that the child's sense of identity is socially and culturally produced. Given that

children spend most of their waking hours in a school setting, I am convinced that school can make or break any child, but most definitely a child with ADHD. To a great extent, schools regulate a child's life and are powerful in determining a child's future — will doors be opened or closed? From nursery school on, the categorization process begins: youngsters are precocious or slow, well adjusted or problematic, and so the screening and weeding are set in motion. The demarcation lines are much more pronounced in high school where the categorization is intentional and even more visible. As you most likely know, ADHD is a pervasive disorder that doesn't conveniently go away with age. It affects every aspect of a kid's life: at home, in the classroom and on the playground. It often makes learning problematic, peer relations stressful and friendships difficult. So many youth with ADHD grow up with a deep sense of embarrassment and isolation, knowing that they are different and because the perception of who they are at home is created by the perception of who they are at school, and because more times than not, this is a negative perception. They carry their difference as shame and frequently feel that they don't belong in either place. If no intervention occurs to shift this view, the sense of alienation and exclusion deepens with time, creating serious psychological and emotional problems and casting the youth's life on a downward spiral from which it is difficult to recover.

On being a child and youth care worker

From having met and dealt with a good number of you over the past several years, I understand all too well the frustrations that you experience because there are far too few of you in the schools and far too many students who need you. There is far too much work for you to do and not enough hours for you within which to do it. There are so many adults — school personnel, teachers and parents — who want you to be responsive to their needs and not enough recognition or rewards for the work that you do manage to do. I know that the pressure and stress of the school environment are great, the burn-out rate amongst you is high, and the demands for your attention on the rise. I know that school budgets are constantly being threatened with cuts, and even when budgets are stable, the cost of needed services far exceeds the available funds. I know also that the school population today presents a multitude of realities, not just kids with ADHD and/or LDs. All of this creates a situation where, as a parent, I inadvertently compete with other parents for your attention. In some kind of ironic twist, I considered myself lucky to be told by the school principal of one of my sons that I would have to wait approximately two years to obtain free testing for my son by the school board because his case was far less critical than some of the other students for whom testing was being recommended. Nevertheless, I am a parent and intent on securing all the assistance, understanding and support possible for my kids to help them succeed.

About your role

I believe that as child and youth care workers, you are critical resources for me as a parent as well as for my boys. I know that I am not the only parent who wants something from you and indeed that requests from school staff, teachers, and parents far exceed your availability, not to mention the requests from the students themselves who don't get enough time with you. I know all this, but when one or other of my sons is struggling through a difficult period, I need to be able to talk with you. Why you, in particular? Well, in my experience, you are the persons who have the most complete picture of what is actually going on with my boys in their lives at school. You are a central source of information at many levels; you hear "it" from the principal, from the teachers, from other kids and even on occasion from other parents. Sometimes you hear it from my kids because they've sought you out (or vice versa) or you are right there when something happens. You are in the "know" and can provide me with the knowledge of my sons' reality at school, both socially and academically. I count on you to give me a reading of how my boys are faring, and though they may not know it now explicitly or even appreciate your presence, my boys count on you too.

I go to workshops, lectures and conferences where I am told that I must be an informed parent, I must know and exercise my rights on behalf of my kids and I must learn to advocate for them. Doctors, educators, social workers, guidance counsellors, researchers, all state that a team approach, and specifically a partnership between the family and the school and even the community, is the best means for my kids to reach their potential and achieve academic and social success.

Some things you can do

I need to feel that you understand the concrete reality of daily living for me. For instance, when I call you, try not to see me as a pest, or an overanxious, bothersome parent. I want you to know that it isn't easy for me to call you, feeling self-conscious that you may see me as a nuisance who is bothering you yet again. Please believe me when I tell you that I try not to call unless I absolutely have to, so when I do, please get back to me in a timely manner.

Give me the benefit of the doubt when I say that I am doing the best that I can as a parent but the fatigue, both emotional and physical, is real and constant. So when enthused, you propose yet another social skills or remedial program that is given twice a week and is forty minutes away by car, don't judge me too harshly when I tell you that I just can't manage it. It isn't that I'm a selfish mom, or worse, that I just can't be bothered; it is that, already stretched beyond the limit, I gingerly walk a tightrope of duties and responsibilities every single day.

Act as a bridge between the teachers and school administration and me. Some teachers and school principals don't know very much about LDs and even less about ADHD. Others are simply more rigid in their

approach to teaching and thus less cooperative and flexible in their dealings and expectations vis-à-vis students in general. This rigidity can have dire consequences for students with ADHD and/or LDs who require accommodations and adjustments in order to have a fighting chance at succeeding.

In recent years, ADHD has been the subject of much media attention while, at the same time, the treatment of this disorder has been the focus of much controversy and debate. The general public has been exposed to tidbits of information on the pros and cons of the currently available treatment options, particularly those that are widely used. This often incomplete picture has resulted in strong positions being taken by various factions in the community at large which has had a marked impact on school staff attitudes towards the disorder itself, especially toward students who purport to have it.

You may be wondering why I am raising this with you now? Some of the media report that the number of ADHD diagnoses has risen dramatically in the last several years, to the point that the question of overdiagnosis or inaccurate diagnosis is being raised along with a concern that Ritalin, the medication usually administered in a treatment plan for ADHD, is being inappropriately recommended, misused or overprescribed for a variety of conditions which are not ADHD. There are many teachers and school personnel who not only question the use of medication, but even the very existence of the condition at all. The consequences are negative, and it is the kids themselves who are the most penalized.

ADHD tends to manifest itself in short attention span, illegible handwriting, and inadequate motor control, that is, in the tasks that are controlled by the frontal lobe that many neuroscientists refer to as the brain's area of executive functioning. This is commonly exhibited in poor organization and study skills and deficits in rule-governed behaviour and task execution. What does all this mean in concrete terms with regard to teachers' expectations? Well, for instance, it may mean that a student with ADHD will submit a page and a half of written work instead of the three that were required for a book report. The teacher needs to know that this page and a half came at great effort and, if it was handed in on time and the work is solid, the ADHD student should obtain a good grade rather than be penalized because his/her report was too short. To those teachers who have told me that this wouldn't be fair to the other students in the class, I say that fair treatment doesn't mean treating everyone the same or, as the saying goes, "There is nothing so unequal as the equal treatment of unequals." If teachers are resistant to making this accommodation, I am asking you to go to bat for my children by helping the teachers understand how daunting it can be for a student with ADHD to produce the same amount and length of homework that is expected from "normal" students. My boys are often enough the focus of negative feedback and attention and, therefore, when they are successful, could you not make it a point to give them lots of positive feedback as often as you can and to urge teachers to do so as well?

My kids need to learn how to advocate for themselves which is a lengthy process, and meanwhile, within the school system, they need you to advocate on their behalf, to look out for their interests knowing that they won't get through without you on their team. If they mess up, show them how to problem-solve and guide them toward more positive alternatives and better choices for themselves.

Youth with ADHD frequently experience difficulty in social situations. Their social interactions can be awkward and sometimes inappropriate which all too often leads to their withdrawal or exclusion from contact with their peers or from participation in group activities. My boys are no exception and though they rarely address what I perceive to be their marginalization, I believe they suffer from it and the loneliness that inevitably follows suit. Like most other youth, they want and need to belong. Unlike many other youth, they don't know how, and worse, they don't know that they don't know how. Whenever possible, even in tiny ways, coach them toward appropriate interactions by modelling such interactions for them and showing them what to do, for they are not instinctively attuned to the dynamics of social interactions nor can they naturally read the cues in social situations.

In the same vein, educate other youth (and yes, other parents, too) when they single out, tease, bully or ostracize students who suffer from disabilities or disorders that cause them to stand out because their differences often make them difficult to be with in a group. Children with ADHD are already at a disadvantage when they come to school and often have a painful time of it. Their poor self-esteem and lack of self-confidence coupled with their social awkwardness make life at school an ordeal for them. They aren't bad or weird, and they don't intentionally set out to cause trouble or disruptions. In fact, they are repeatedly bewildered when reprimanded for actions and behaviour that they were unaware were problematic. Teach others — youth, parents and school personnel alike — to see these kids as persons who were born with disabilities or disorders that they didn't choose to have. My boys have ADHD, yes, but often the kids they meet or the people who deal with them only see my boys in terms of their disorder, and thus the ADHD becomes the defining feature of who they are. I am asking you to help the kids and adults who have contact with my sons to see beyond their ADHD and treat them as persons who have much to offer if welcomed and given the opportunity to do so.

Lastly, as you may have already gathered, I feel that I have had more than my fair share of "I'm sorry to have to tell you that your son did such and such" calls and notes to the same effect sent home about my sons. It certainly would be wonderful to hear from you if you have some positive reports to offer about my boys.

So, please, when there is good news about them to relay, call me or send me a brief note so that we can celebrate their hard-won successes with hope and encouragement about their future.

A concerned Mom

Some suggested further readings and useful information:

The following are mainly references for educators and youth care professionals with the exception of a few references aimed at parents:

1988

Goldstein, A.P. (1988). *The prepare curriculum: Teaching prosocial competencies*. Champaign, IL: Research Press.

1994

Jones, C.B. (1994). *Attention deficit disorder: Strategies for school-age children*. Tucson, Arizona: Communication Skill Builders.

Through classroom accommodations and instructional approaches, Dr. Jones proposes educational strategies that build on students' strengths to promote successful learning and the development of effective coping skills.

Levine, M. (1994). *Educational care: A system for understanding and helping children with learning disorders at home or in school*. Cambridge, MA: Educators Publishing Service.

The book presents a developmental model based on clinical, educational, and research experience, that favours informed observation and description over labeling of children with learning problems. Twenty-six common, observable phenomena grouped according to educational themes are discussed followed by suggestions for collaborative management of these children by parents and youth care professionals and educators.

1995

Hallowell, E. M. & Ratey, J. J. (1995). *Driven to distraction*. New York, NY: Touchstone.

A book about ADD written by two psychiatrists who have ADD that is informative, practical and hopeful and makes ADD comprehensible.

1998

Goldstein, M. & Goldstein, S. (1998). *Managing attention deficit hyperactivity disorder in children: A guide for practitioners*. New York, NY: John Wiley & Sons, Inc.

1999

Parker, H.C. (1999). *Put yourself in their shoes*. Plantation, FL: Specialty Press, Inc.

A book that provides a great deal of helpful information about understanding the world of teenagers with ADHD and how ADHD affects the lives of adolescents at home, at school, and in social relationships. This easy-to-read book gives the reader a sense of what it is like to be an adolescent with ADHD and includes strategies to foster problem-solving, communication, study, and social skills in teenagers.

2000

Andrews & Lupart, J. (Eds.). (2000). *The inclusive classroom: Educating exceptional children*. Scarborough, Ontario: Nelson Thomson Learning. Second Edition.

This book provides a comprehensive overview of inclusion, practical strategies to implement in the classroom and valuable knowledge to assist teachers and child care professionals to guide and encourage youth towards success.

Barkley, R. A. (2000). *Taking charge of ADHD: The complete, authoritative guide for parents*. New York, NY: Guilford Press. (Revised edition).

A book for parents that offers them the most up-to-date information, expert advice and useful approaches to ensure appropriate interventions and quality care for their children.

Brown, T. E. (Ed.) (2000). *Attention-deficit disorders and comorbidities in children, adolescents, and adults*. Washington, DC: American Psychiatric Press, Inc.

This book covers the latest findings on ADHD in combination with the full range of other psychiatric and learning disorders ranging from preschoolers to adults. It is oriented to health care professionals who need up-to-date information on ADHD and related comorbid disorders and disabilities.

Dendy Zeigler, C. A. (2000). *Teaching teens with ADD and ADHD*. Bethesda, MD: Woodbine House, Inc.

This is a quick reference guide for teachers and parents that contains practical advice and effective strategies for home and school. The book contains many useful tips, including appendices with helpful tools and materials that facilitate the work of teachers, school personnel and mental health professionals in promoting a positive learning experience for youth with ADHD.

Parker, H. C. (2000). *Problem solver guide for students with ADHD*. Plantation, Fl.: Specialty Press, Inc.

The focus of this book is on elementary and secondary school students who have ADHD and includes many classroom accommodations and strategies to improve attention, behaviour, and performance.

CH.A.D.D. (Children and Adults with Attention Deficit/Hyperactivity Disorder). www.chadd.org. This is an excellent source for education, research, information and advocacy. This international organization puts out an information and resource guide on all aspects of ADHD, including fact sheets and a comprehensive set of articles. CH.A.D.D. also puts out the *ATTENTION* Magazine which includes articles by the leading authorities in the field of ADHD and co-occurring disorders.

NICHCY (National Information Center for Children and Youth with Disabilities). This is an information clearinghouse that provides free information on disability-related issues. The focus is on children and youth with disabilities from birth to age 22. NICHCY's services include referrals to other organizations, responses to questions on disability issues, and information searches of its databases and library. Tel: 1-800-695 0285; e-mail: nichcy@aed.org. Website: www.nichcy.org