

Meeting the Challenges of AD/HD

By Evelyn Green

Editor's note: This article is excerpted from a speech delivered at the National Institute of Mental Health Conference in April in Chicago, IL. For the [complete version](#) of the speech, visit the CHADD web site at www.chadd.org. The name of the author's son is withheld by request.

I am an early childhood educator and consultant, children's advocate, member of the Chicago Metro Association for the Education of Young Children, Secretary of the National Board of Directors of CHADD, chairperson of CHADD's 12th Annual International Conference, and founder of the Chicago CHADD chapter. Although I am proud of my accomplishments, I don't list them to impress you, or even because I believe that they are particularly important, but rather because they remind me of the most important role I play every day -- that of a mother. Everything I do in all my other roles is deeply affected by that fact, and the title of which I'm most proud is "Parent."

The older of my two wonderful sons has AD/HD, a diagnosis that in some way has touched every person and event in our lives. I am here with the permission of my child because he understands the importance of this meeting. He also recognizes and acknowledges that he has attention-deficit/ hyperactivity disorder and understands the unique challenges that the disorder presents in all facets of his life every single dayÉ and if sharing our family story can make a difference for him and others with AD/HD, then in his words, "it's worth it."

Like all new parents, from the moment we brought our child home, we knew he was specialÉ. But we had no idea just how special he really was. Because of my background in early childhood education, I realized early that something was not "quite right." He didn't interact like other children his age. He was unbelievably stubborn and his speech development, although not delayed, was by no means normal. Just imagine waiting to hear those all-important first words, "mama" or "daddy," and hearing "Pontiac" instead! His temper tantrums were long and uncontrollable, yet he could be the sweetest, most loving child in the world.

None of the standard behavior modification techniques seemed to work. We struggled with the notion of being bad parents, especially since we were often accused of just that by well-meaning friends and family, not to mention total strangers. Eventually my husband and I realized we could not do this alone and sought help from everyone imaginable, including our families and pediatrician, social workers, educators and psychologists. Finally, one of his teachers suggested we have him evaluated for AD/HD. It took more than five years of struggle, doubt and worry before our son was diagnosed with AD/HD at the age of seven.

Because my husband was fortunate enough to have a wonderful insurance plan, we obtained our diagnosis from a nationally known AD/HD center at a major university teaching hospital. There are no words to describe the relief that we felt to have a name for our son's behavior, to finally have a plan to help him and, most of all, to know that it was not our fault.

Correct diagnoses of brain disorders are difficult at best. In my community they are often impossible to obtain. Minority populations, African Americans in particular, and the poor do not seek or receive adequate levels of diagnosis and treatment for mental illness. For a variety of reasons, including insurance coverage issues, cultural differences and an understandable mistrust of the medical community, especially regarding mental health issues, diagnosis and treatment of brain-related disorders like attention-deficit/hyperactivity disorder is far below the national average in these communities. Aggressive research is needed to make diagnosing brain disorders more definitive, less subjective and easier for clinicians. There have been major breakthroughs in recent years in brain imaging, gene therapy, and other potential diagnostic techniques.

Once our son was diagnosed with AD/HD, the real fun began. We were given treatment options, which included behavior modification, social skills training and parent training. Again, we were fortunate because our insurance covered the cost of all mental health services. We were sent to a medication clinic so the staff could determine if our son was a candidate for pharmacological intervention and to set up a medication trial. The clinic staff explained all the options available to us and gave us lots of materials and resources, but deciding to medicate our child was still an overwhelmingly difficult choice. Reluctantly, we went ahead with the medication trial, but with the understanding that we would stop the meds at the first sign of adverse effects or if they didn't seem to make a difference.

In retrospect, I am angry that we even had to experience those doubts and confusion over the medication. Parents naturally recoil from the idea that young children need medical intervention to control their behavior. Yet, if our children were diabetic and needed insulin, or needed cancer treatment medication, or even needed glasses or hearing aides, we would not hesitate to provide them. I am also angry that I really can't be sure that my child won't have some long-term effects from his medication. While we have over 50 years of research on the effects of Ritalin and other stimulants, the truth is we really don't know how these drugs will affect our children later in life. As parents and clinicians, we need those answers to make the job of prescribing and giving medication less traumatic.

Finding the correct medications and dosage, setting up a behavior modification program, and providing social skills and other training through working with a psychologist were a good beginning for my son. But disorders such as AD/HD often affect these children the most in school -- the area where parents and clinicians typically have the least understanding or control. In my son's early school years, we were fortunate to have good teachers who were willing to accommodate his "differences."

They recognized and appreciated his intelligence and creativity and found ways to work around his disorganization, impulsivity and inattentiveness to help him succeed academically.



In the fifth grade, however, we got a teacher who was determined that the only way was her way. She had no patience or tolerance for any child who was different. She taught strictly by the book as well as from the book, and creativity was not permitted in the children or in her teaching style. By December of that year, our son had gone from a relatively happy, engaged youngster to a depressed, anti-social, miserable monster. He stopped believing in himself or in our ability to protect him. He

constantly acted out and got into fights and altercations at home and school. His once healthy self-esteem became non-existent. Finally, at 11 years old, my beautiful child decided that he'd had enough and threatened to commit suicide. I thank God every day that he did threaten before he acted, or he might not be with us today.

Because I saw that the change in our son was a direct result of his school experiences, I immediately requested a case study evaluation to determine eligibility for Special Education services. Until this time, I had resisted having him "labeled" by the school system. After all, I worked for these people and had seen what happened to kids, especially little black boys with special education placements. There was no way I would allow my child to be placed in an "emotional or behavior disorder" program, and what I had seen in the various learning disabilities classrooms was not much better. But now I had no other choice if I wanted to protect him from further emotional damage. Luckily, my association with CHADD helped me to understand my rights and I knew that he could qualify and receive services in a regular education classroom through a classification under the "other health impaired" category. Despite my knowledge and understanding of the system, it was still difficult to get him the proper placement with all of the appropriate accommodations and interventions needed to help him succeed. I cannot imagine what an impossible task this must be for parents without that knowledge and understanding.

It is so clear that what happens to these children in the classroom has a tremendous impact on their ability to cope with their disorders. It is also clear that for many parents, the first indication of a problem occurs once a child begins school. It is imperative that we find ways to help classroom teachers understand how to identify and work with these children to maximize their educational experiences without worsening their conditions. We need data to design new programs and strategies that will help our children become successful academically as well as in the other areas of their lives. How many children, whatever their race and socioeconomic backgrounds, could have their educational needs met in regular programs if they had teachers armed with the strategies to help them succeed.

Despite finding the right medical, psychological, behavioral and educational interventions for our son, our family still struggles every day with this disorder and its many ramifications. While there are no definitive answers yet, we do know that genetics plays a role in disorders such as AD/HD and when a parent's problems are compounded with the child's problems, the effect can be devastating. Our family is no exception.

As a child, my husband struggled in school with what we now know to be undiagnosed learning disorders and possibly AD/HD as well. As an adult, he struggled for years with depression that only got worse as our child's problems became more complicated and demanding. Despite the understanding and support he always gave our son, he never sought treatment himself. As a black man, he was fearful of both the mental health community and the stigma associated with mental illness, especially in our community. He began the all too common practice of self-medicating with drugs and alcohol and at one point attempted suicide. Eventually his problems with substance abuse led to encounters with the criminal justice system.

As a result of these problems, he is no longer a part of our daily lives. I want to be very clear here—we are NOT talking about a gang-banger or deadbeat, absentee father. He is a man who had a successful career, was active in his community and was a terrific and supportive father and husband. He coached baseball, took care of the children while I attained all of those degrees and became active in organizations like CHADD. Yet, despite all he knew and learned as a result of our son's mental health issues, he STILL felt unable to freely take advantage of the services and treatment available to him. As a result, our family is left trying to cope with his absence, which we feel on a daily basis. We miss his physical presence as well as his emotional and financial contributions. My son is left with yet another burden to bear as he struggles through these teenage years without the father he had come to rely on throughout his life.

I now know that our experience was not typical of what other urban, minority and/or poor families experience in terms of the diagnosis and treatment process. After talking to literally hundreds of parents, it is clear to me that we need to find ways of improving the availability and delivery of these services in our communities. On an even more basic level, we need to gain an understanding of the barriers to mental health services in these under served populations and find ways to eliminate them.

While there are some families like ours, fortunate enough to have the resources and know-how to access services, many more do not even know such help is available, let alone how to obtain it. We need to know exactly what services are available and how we can help parents find them. Collaboration with key agencies and institutions such as schools, churches and neighborhood centers in our communities is vital to this effort. I know how important the support I have received from being a member of CHADD has been for both my boys and me. I'm quite certain we never could have survived the last few years without that support. There is a desperate need to both identify how we can offer support to families and then to ensure that support is available to all segments of our community.

I think it is important to tell you that my son is now a freshman in one of the top college-prep high schools in the city, participating in debate, drama and youth in government activities. Each day he rides the commuter train to school. On the way, he picks up a copy of USA Today and New York Times to read before he gets to school. Although he still struggles academically, he has fully regained his self-esteem, sometimes to a degree that is actually frightening! In fact, he told me just the other day, that while he knows his GPA isn't the best, he was sure he'll get into the highly competitive summer programs he's applied to because he has so many other great things going for him!

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