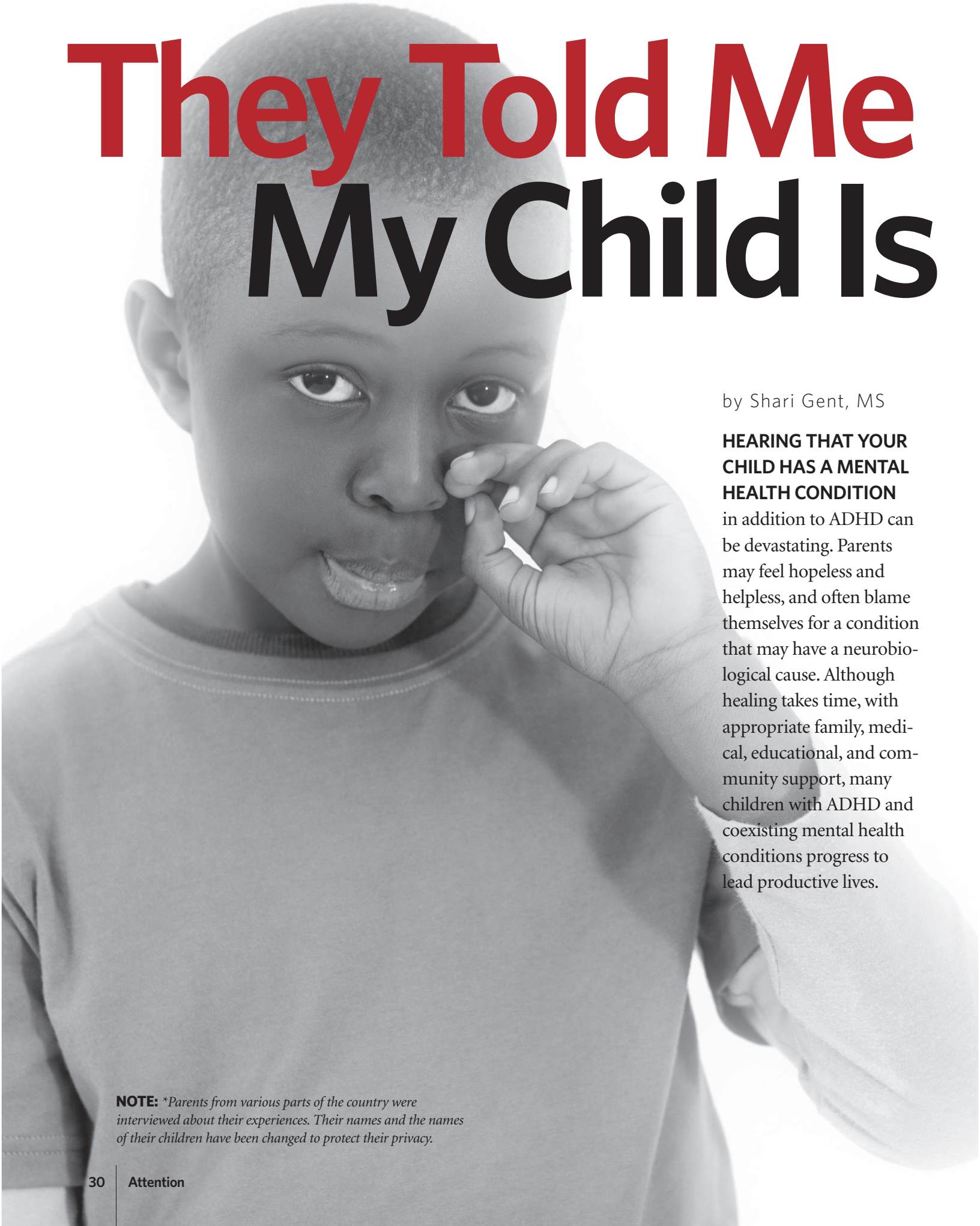
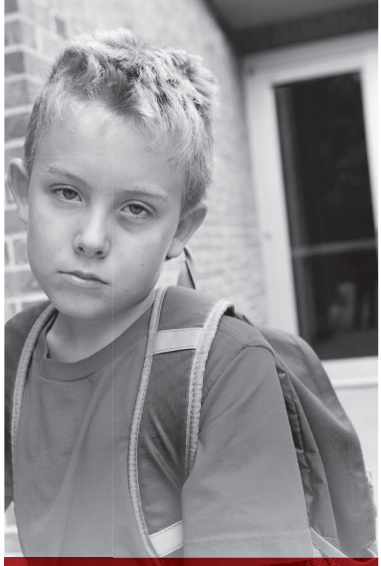
They Told Me My Child Is



by Shari Gent, MS

HEARING THAT YOUR CHILD HAS A MENTAL HEALTH CONDITION in addition to ADHD can be devastating. Parents may feel hopeless and helpless, and often blame themselves for a condition that may have a neurobiological cause. Although healing takes time, with appropriate family, medical, educational, and community support, many children with ADHD and coexisting mental health conditions progress to lead productive lives.

NOTE: **Parents from various parts of the country were interviewed about their experiences. Their names and the names of their children have been changed to protect their privacy.*



Disturbed

ADHD with Other Mental Health Conditions Goes to School

Lyssa* took her son Kenny* out of a private kindergarten when classroom parents threatened to have him removed because he disrupted other students. "Every time he was asked to write, he burst out crying," she recalls. Kenny was diagnosed with fine motor difficulties, ADHD, and depression. When Lyssa enrolled him in public school, he was placed in a general education class.

Changing schools was not a solution. After numerous outbursts, the school recommended placement in a class for children with emotional disturbance. Lyssa visited the class, but came home in tears: "I knew it wasn't the right place for Kenny, but none of the other private schools would take him." Kenny continued to cry and to have outbursts when he felt he was treated unfairly, and Lyssa decided she needed to obtain an IEP.

ADHD and mental health

While ADHD, the most commonly diagnosed mental health condition in children, has become more accepted and even embraced by some families, coexisting conditions such as depression, anxiety, reactive attachment disorder, and bipolar disorder continue to carry considerable stigma. Parents are often afraid that the label will follow their child throughout his or her life, affecting self-esteem and opportunities for employment. Additionally, families may fear that placement in special class will fail to meet their expectations of an appropriate educational setting for their child.

The reality is that fully one-third of the general population will be diagnosed with a mental health condition at some time during their life. Emotional disturbance, better known as emotional/behavioral disability (EBD), is one of the thirteen conditions that can qualify a child for special education services under the federal law, the Individuals with Disabilities Act (IDEA 2004). While just one percent of the school population qualifies for special education as a child with EBD, fully twenty percent of students will experience an emotional or behavioral condition that will interfere with their ability to learn at some time during their school career, according to the National Institute of Mental Health (NIMH).

For children with ADHD, this number is more than one-half, according to the National Alliance on Mental Illness (NAMI). A small number of these students will qualify for special education as having an emotional/behavioral disability. Most will experience emotional difficulties that are not severe enough to qualify for EBD services, but continue to affect the student's ability to make and keep friends and perform academically. To complicate matters, many symptoms of depression, anxiety, and abuse may mimic ADHD. ADHD itself can cause problems with emotional regulation; distinguishing between ADHD with emotional regulation problems and other mental health disorders requires professional expertise.

Mental health conditions affecting children and teens with ADHD fall into two primary categories: disruptive behavior disorders and mood disorders. Until May 2013, ADHD was grouped with disruptive behavior disorders in the Diagnostic and Statistical Manual IV (DSM-IV), the resource used by professionals to diagnose mental health conditions. Published in May 2013, the new DSM-5 groups ADHD in the neurodevelopmental disorders category. This is an important recognition that ADHD has a biological cause rather than simply being a constellation of behaviors. Recognition of neurobiological nature of ADHD may alleviate some of the stigma that many still attach to the diagnosis. The new classification may also make the diagnosis more credible to those who continue to doubt its existence.

Although the neurobiological causes for ADHD have been sanctioned, the lines between ADHD, disruptive behaviors, and mood disorders are not distinct. Approximately forty percent of youth with ADHD also have oppositional defiant disorder, according to CHADD's National Resource Center on ADHD. Conduct disorder, a more severe behavior problem that can develop in a child with ODD, affects twenty-five percent of children and up to forty-five to fifty percent of teens. The most prevalent mood disorders affecting children and teens with ADHD are depression (ten to thirty percent) and anxiety (thirty percent). Bipolar disorder is a less frequently occurring but serious condition, affecting up to twenty percent of individuals with ADHD. See the sidebar on page 32 on when to seek a mental health evaluation for your child.

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Tory's experience

Shannon and her husband adopted their first child when he was nine months old. Although he was born in Guatemala during the civil war, they did not suspect that their beautiful, healthy boy had an anxiety disorder. In retrospect, Shannon suspects that as an infant, Tory may have experienced the terror of house-to-house searches. When he was diagnosed with ADHD in second grade, Tory continued to do fine in school and at home. At the beginning of fifth grade, however, when he was punished for forgetting to bring pencils to class, Tory broke down.

In his Midwestern school, fifth grade is the year when executive function demands increase exponentially. Suddenly, Tory had to go to six different classes with six different teachers and store his books and materials in a locker. "When I picked him up on the second day of school, he just fell apart," Shannon recalls. "He couldn't remember his pencils or his work. He was terrified to go to school. He acted like a cornered animal."

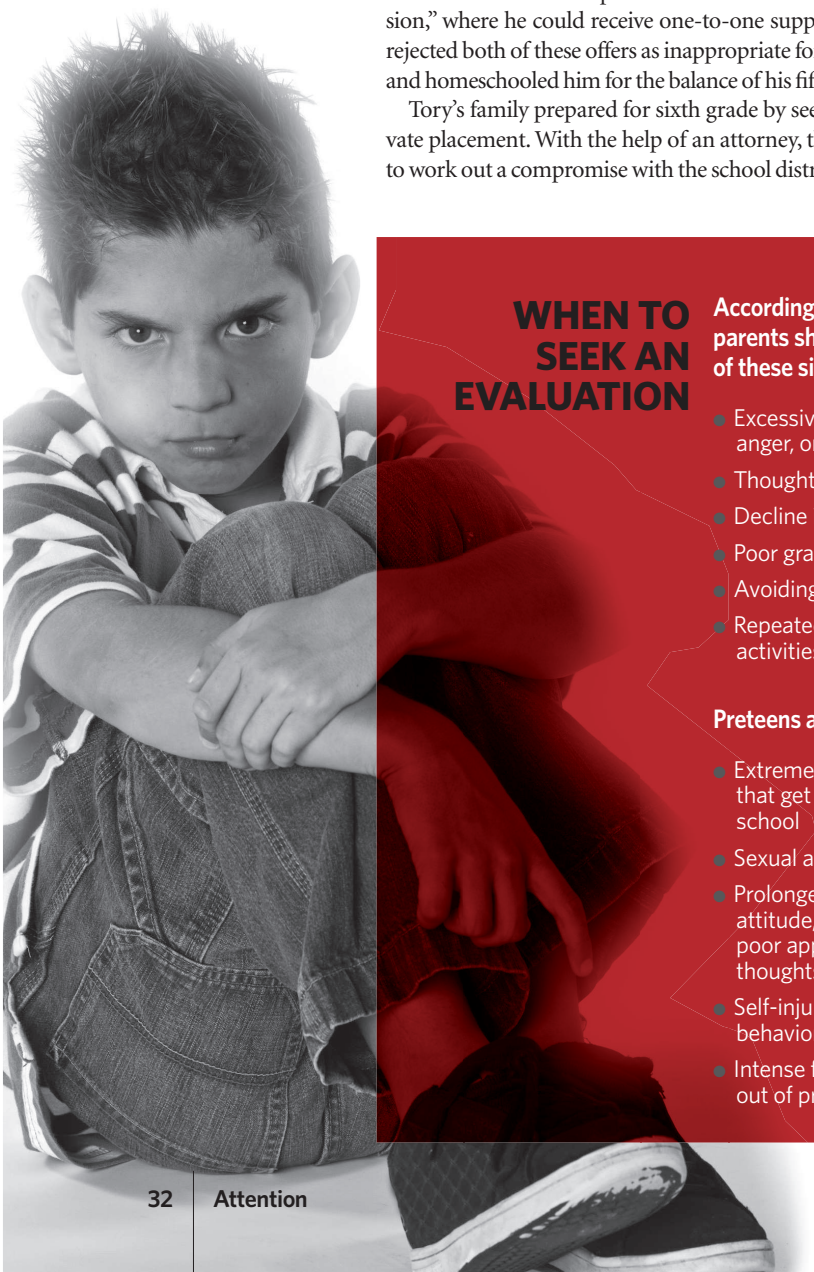
After Tory was diagnosed with post-traumatic stress disorder, a type of anxiety disorder, he and his family were gradually able to put the pieces of his life back together. The school offered alternative placement at a site that focused on juvenile offenders or time at his previous school in "in-house suspension," where he could receive one-to-one support. Shannon rejected both of these offers as inappropriate for Tory's needs and homeschooled him for the balance of his fifth-grade year.

Tory's family prepared for sixth grade by seeking out private placement. With the help of an attorney, they were able to work out a compromise with the school district. "The staff in the sixth grade was completely different," says Shannon. "We connected with a wonderful resource guidance counselor who understood mental health issues. She was only available at teacher request. In this case, the superintendent requested." Along with new medication, this connection with a trusted adult at school enabled Tory to overcome his fears and experience success.

Quality programs for students with EBD

If your child or teen has been diagnosed with coexisting mental health conditions, support from a mental health professional is essential. But what about school? What are the types of programs that have been demonstrated to provide these students with the best possible education? The solution is different for each child, but research has identified some basic components that characterize quality programs for students with emotional difficulties. These include:

- A focus on developing healthy interpersonal relationships between students and supporting adults and between students and their peers
- A highly structured and predictable environment
- Evidence-based academic instruction aligned with regional or national standards
- Appropriate accommodations for individual needs
- Positive behavioral supports; check to see that all personnel, including instructional assistants receive periodic training
- Opportunities for social and emotional learning experiences



WHEN TO SEEK AN EVALUATION

According to the American Academy of Child and Adolescent Psychiatry, parents should consider seeking a mental health evaluation if they notice any of these signs in their young child:

- Excessive worry, frequent crying, anger, or fearfulness
- Thoughts of suicide
- Decline in usual school performance
- Poor grades despite trying very hard
- Avoiding other people
- Repeated refusal to attend school or activities
- Unexplained changes in eating or sleeping
- Frequent, unexplained temper outbursts
- Need to perform certain routines many times throughout the day
- Persistent nightmares

Preteens and teens may exhibit the signs listed above as well as the following:

- Extreme difficulties in concentrating that get in the way at home and at school
- Sexual acting out
- Prolonged, negative mood and attitude, often accompanied by poor appetite, difficulty sleeping or thoughts of death
- Self-injury or other self-destructive behavior
- Intense fear of being obese that is out of proportion to actual body size, excessive dieting, vomiting or using laxatives to lose weight
- Repeated threats to run away
- Repeated use of drugs and/or alcohol
- Aggressive or nonaggressive consistent violation of the rights of others; opposition to authority, truancy, or vandalism
- Strange thoughts, beliefs, or unusual behaviors

QUESTIONS TO ASK WHEN CONSIDERING SCHOOL PLACEMENT

Make a list of questions to ask before visiting a potential general or special education classroom to be sure the placement will meet your child's needs. Suggested questions include:

- Is the classroom environment well organized? Is there a specific area for each type of activity? Is there a quiet area where students can go to take a break? Are the exit pathways clear of clutter?
- Is student work displayed?
- Is the daily schedule clearly posted and does the teacher refer to it? Are the classroom behavioral expectations (rules) clearly posted and referred to?
- How does communication with parents about daily behavior take place? About special events? What if my child loses his note home—is there an alternative way to communicate?
- What is the homework policy? Will my child be penalized for forgetfulness if he can otherwise demonstrate mastery?
- What type of positive classroom behavior system is in place? Many self-contained classrooms use a "level" system. This sort of system can be effective, but must be implemented to minimize risks that a child may get "stuck" at the bottom rung. To encourage growth, there should be a way for a child to make progress even at the lowest level. To compensate, some classrooms also incorporate a point system at this level.
- How are individual behavior plans (Behavior Intervention Plans or BIPs) implemented by staff? Is there evidence of behavioral data-keeping or behavior logs?
- What procedures are used for a behavioral emergency?
- If this is a self-contained classroom, is there a "time-out" room? If so, this should be used as a last resort and definitely be without a door and unlocked. Find out when and why it might be used.
- What accommodations are available? Will these meet my child's needs? For example, if my child has difficulty waking up in the morning, because of his mental health condition or medication, can his schedule accommodate a late start without penalty? If my child needs shortened work periods, is an activity provided when the work is completed?
- How much time is spent on academic instruction? How is this individualized? Are hands-on, multisensory activities that appeal to an active learning style regularly available? Even older students need opportunities for experience-based learning.
- Is there a social skills or social-emotional learning curriculum in place? Is this a published curriculum? If so, what are the components? Some schools provide this experience in the general class, some in a lunch group. Does communication with parents take place about topics being covered?
- What is the adult to child ratio? Do all staff receive training in behavioral principles?
- Can my child have access to a trusted adult when he or she needs time to debrief or talk about a troubling experience?
- How long are the work periods? Are movement breaks available? Relaxation activities?
- What about recess? If my child is easily threatened by the noisy playground, is an alternative quiet recess available? If my child is boisterous and benefits from exercise, is recess withheld to manage behavior or as a consequence for failure to complete work? If so, what alternatives can be arranged?

- A curriculum that includes life skills/career education
- Frequent communication between home and school
- Collaboration between all treating professions and the family

Be sure to read the sidebar (page 33) on questions to ask when considering a potential general or special education placement for your child.

Persistence pays off

For Lyssa, Kenny's mother, tireless effort for several years finally paid off. In his initial placement, she recalls, Kenny "would cry, then curl up in the fetal position. But the school district said that is the only class we think is appropriate." Although there was a high adult-to-child ratio, the classroom behavior system was punitive. "The expectation that a child with ADHD could maintain perfect behavior for seven weeks to move up a level is unrealistic. It was just so not right for a student with ADHD," she says. "Kenny's disability is executive functioning. The school was not remotely considering this."

Finally, after a long wait, the family was able to enroll Kenny in a university-based school designed for children with ADHD. "The difference is that when the day is over, it's over," says Lyssa. "You can turn around behavior. You can recover. You can let it go." Parent participation is encouraged and parent training is required. Kenny is now in third grade and plans are being made to transition him back to a general fourth-grade class in the neighborhood public school next year.

Shari Gent, MS, *is an education and behavior specialist with the Diagnostic Center, Northern California, California Department of Education. As a CHADD volunteer, she coordinates a parent support group, teaches Parent to Parent classes, and serves on the board of the Northern California chapter and the editorial advisory board of* Attention *magazine.*

Additional Resources

CHADD (chadd.org) and the National Resource Center on ADHD (help4adhd.org)

National Dissemination Center for Children with Disabilities; NICHCY Disability Fact Sheet #5, nichcy.org

National Alliance on Mental Illness (NAMI), nami.org

The Balanced Mind Foundation: Family Resources for Our Kids with Mood Disorders, thebalancedmind.org

Lisa Boesky, *When to Worry: How to Tell If Your Teen Needs Help and What to Do About It* (AMACOM, New York, 2008).

R. Neel, K. Cessna, J. Borock, and S. Bechard, "Quality Program Indicators for Children with Emotional and Behavioral Disorders," *Beyond Behavior*, Spring 2003