

AD/HD

Diagnosis and medication aside, it's clear the condition interferes with learning

BY GLENN COOK

The first-graders are sitting in rows, counting to 100. Several are trying to get settled as the school day begins. One little boy looks aimlessly around the room, restlessly moving around in his spot. "10, 20, 30, 40," the children chant in unison as they move toward the 70s, when they will start counting by ones.

The teacher spots the boy, then says to no one in particular, "You need to pay attention. Eyes up here." But the boy can't pay attention no matter how hard he tries.

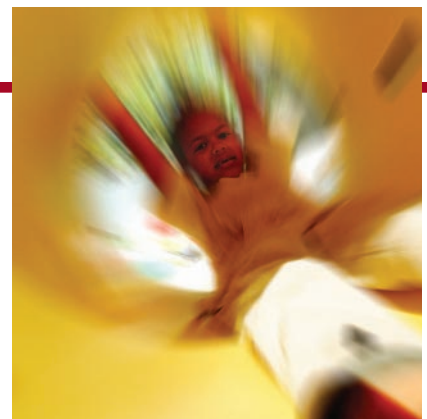
He is one of approximately 2 million school-age children diagnosed with attention-deficit hyperactivity disorder, commonly known as AD/HD. A condition characterized by inattention, hyperactivity, and impulsive behavior, AD/HD affects 3 to 5 percent of children in the

United States, according to the National Institute of Mental Health (NIMH).

"AD/HD is a chronic disorder that makes a child unavailable to learn," says Patricia Quinn, a developmental pediatrician in Washington, D.C., and author of numerous books on children with AD/HD. "The teacher may have presented and taught something with the child physically present.

But if the child is not there mentally, then the child is not available for learning."

Despite being the subject of research for more than 100 years, AD/HD remains one of the most controversial diagnoses for educators and parents. Questions surround the use of medications as part of treatment, the proper way to identify AD/HD, and the role of educators in helping children who disrupt



classes and learning.

Quinn, cofounder of the National Center for Gender Issues and AD/HD, says the disorder is "an explanation, not an excuse."

"A lot of people think we're trying to make excuses for kids, to get them out of something they should be doing. That's not it at all," she says. "We're trying to find ways to help them succeed. We need to take the explanation and work to find out how they can best show us what they know."

A BRAIN-BASED DISORDER

A generation ago, in most classrooms, that restless first-grader would have been told to sit down and be quiet. If he could not control his behavior, he would have been sent to the office, separated from his peers, or

suspended from school.

Some think this should still be the schools' approach and complain about out-of-control children running roughshod over teachers and classrooms. In fact, a significant number of Americans—20 percent—believe AD/HD is a made-up disease pushed by drug companies in an effort to medicate children, according to a 2004 Kaiser Family Foundation poll.

A significant, though smaller, number of teachers agree. In a 2002 survey conducted by Feinstein Kean Healthcare, a Cambridge, Mass.-based health-care public relations firm, 11 percent of teachers said they do not believe AD/HD is a legitimate medical condition. Eighteen percent said they believe poor parenting is the cause.

"The mental health field is still faced with a significant stigma against identifying a child as having depression, AD/HD, or bipolar disorder," says Clarke Ross, chief executive officer of Children and Adults with Attention Deficit/Hyperactivity Disorder (CHADD).

"I remember when cancer and epilepsy had a major stigma," he says. "I remember when AIDS had a major stigma. Mental health conditions still have that stigma, despite all of the research."

That research, physicians and mental health officials say, points to a strong neurological and genetic basis for AD/HD. Under current guidelines, AD/HD has three recognized subtypes: predominantly inattentive, predominantly hyperactive/impulsive, and combined. Environmental factors may contribute to its severity, and as many as two-thirds of children have one or more additional disorders, including depression, oppositional defiance, or learning disabilities.

"There is an increasing understanding that these are brain-based disorders, and research shows that this is not just poor parenting," says Karen Miller, assistant professor of pediatrics at the Center for Children with Special Needs, based at Tufts-New England Medical Center in Boston. "Poor parenting and poor teaching make it worse, but they don't cause AD/HD."

CHADD, based in Landover, Md., is an example of how AD/HD's reputation has evolved in the medical and mental health

communities. Started by two Florida physicians as a parent support group in 1987, the organization came under fire in the mid-1990s after revelations that much of its funding came from drug companies.

Today, CHADD has 20,000 members and 235 chapters in 43 states. It is supported by such groups as NIMH and the American Academy of Pediatrics. The National Resource Center on AD/HD, which CHADD oversees, is funded by the Centers for Disease Control and Prevention.

"Our critics deny the existence of mental disorders and claim that these disorders don't exist, that psychiatry is all a front to sell medications," Ross says. "What we advocate is based in science, and what science

advocates is a [multifaceted] approach to treat this disorder. It's not just medication. It's medication when appropriate."

Quinn agrees. "In the past, we have made the mistake of only medicating children, only to learn that there are no easy answers in treating AD/HD," she says. "You can't just medicate the child without other modifications. That doesn't work."

DIAGNOSING AD/HD

One of the most confusing—some would say confounding—things about AD/HD is its ever-evolving name. It has been dubbed, at one point or another over the past 40 years, minimal brain damage, minimal

The gender question

It's a boy thing. Or at least that's what we think.

Three of four children diagnosed with AD/HD are boys, and a majority of the general public and teachers believe the disorder is more prevalent in males than in females, according to a 2004 Harris Interactive poll.

But, according to physicians and organizations such as the National Institute for Mental Health, girls are more likely to be undiagnosed because of the way they present themselves in society and at school.

"If you're focusing on hyperactive behavior, you miss all the girls who have attention or focus problems," says Patricia Quinn, cofounder of the Washington, D.C.-based National Center for Gender Issues and AD/HD. "Girls are underdiagnosed because they don't always present disruptive behavior."

Boys with AD/HD are generally more aggressive in their play and more active in general than girls who have the disorder, Quinn says. Girls tend to internalize issues, have more peer problems than boys, and be more aware that they are "different."

"It's not seen as strange for boys

to act impulsively and ride on the hood of a car on Main Street at 2 a.m.," Quinn says. "For a girl, there is no excuse. She is ashamed, her mother is ashamed, and society is ashamed over her behavior."

"Boys are more expressive in how they react to things," she adds. "If a boy is having trouble with a teacher, he'll come home and say the teacher is stupid. If a girl is having trouble, she will come home and say the teacher doesn't like her. If a boy does poorly on a test, he'll say it's a stupid test. The girl will come home and say, 'I'm stupid.'"

Quinn's center focuses on educating women, parents, and teachers on the role gender plays in diagnosing and treating the disorder. By making teachers aware of how girls with AD/HD behave, Quinn hopes to avoid secondary problems that can lead to depression and other problems in adulthood.

"If you can make people more aware of the differences between boys and girls, and find ways to get these kids the help they need early on, then you can avoid a whole host of problems down the road," she says. "If you don't, then these problems will emerge at some point, and the effect will be life lasting."—G.C.

brain dysfunction, restlessness syndrome, and hyperkinetic impulse disorder. Until recently, AD/HD and ADD (attention deficit disorder) were considered separate diagnoses; today, AD/HD serves as the umbrella for all facets of the disorder.

In 2000, the American Academy of Pe-

diatrics published guidelines for diagnosing children with AD/HD. Among them: Academic or behavioral struggles in school should play a role; and evaluations are needed from multiple sources, including parents and teachers.

Because it is impossible to determine by

genetic testing whether a child has AD/HD, behavior is carefully analyzed instead. The Conners' Rating Scales, a series of questions physicians give to parents and teachers when a child is being evaluated, are the most widely used tools. On a zero-to-three scale, students are rated for inattention, hyperactivity, perfectionism, and oppositional, anxious, or shy behaviors.

"Often school is the place where the first step toward identification occurs, because the school setting is usually where the child is struggling," says Miller, who has worked as a consultant to districts in Massachusetts, New York, and Virginia. "Teachers have a [group of kids] to work from and they can see the impairment, where at home it may be much less evident or much more tolerated."

However, a teacher's word is not enough for physicians to make a definitive assessment. Miller and others say boards should provide training for teachers on how to approach a family when a child is struggling in class and may need to be referred to a health care professional for a formal evaluation.

"It's been shown that teacher reports are more reliable than parent reports, but that's not 100 percent," Miller says. "You have biases in both directions, so you need multiple sources. You need to look for chronic issues because this is a chronic disorder."

TO MEDICATE OR NOT TO MEDICATE

Deciding whether to medicate a child for AD/HD is often an agonizing decision, and no one knows that better than Dayna Miller, a school board member from Kansas' Basehor-Linwood Unified School District.

Miller (no relation to Karen) has two children on medication for chronic conditions. Her daughter, now in fourth grade, has asthma and uses an inhaler. Her son, who is in first grade, is taking Concerta, a stimulant medication used to treat AD/HD.

"He's on a perpetual treadmill," she says. "Mornings are terrible until the medication kicks in. He has no control. He can't sit still to eat breakfast. He's moving constantly. He has no concept of time or a schedule until the medication kicks in. Then he's just fabulous."

Miller said her son's signs surfaced when he was 3. A stay-at-home mother, she

A charter solution

Peter DiMezza knows the frustrations parents feel. A licensed clinical counselor who spent 12 years working with children and adults with AD/HD, he has heard plenty of war stories about students who could not be successful in the regular school setting.

So, in 1998, DiMezza founded the Summit Academy, a charter school in Akron, Ohio, that serves children with AD/HD and Asperger's Disorder, a mild form of autism. The school has since expanded to 18 sites and now serves more than 1,000 students across the state.

"We've found that the kids who came to our schools were kids with the most severe type of AD/HD and Asperger's who were not successful in their previous school setting," DiMezza says. "Now they love coming to school. The parents are happy, and we've started seeing the kids do better academically and socially."

Summit schools have 15 students per class, with a teacher and an aide in each room. Lessons are designed to be stimulating, with students spending 20 minutes each on several units during the day. Sign language is used because it helps students use both sides of the brain.

DiMezza says Summit officials do not "promote or discredit" the use of medication.

"Most parents say they would like for their child to come off medication. We would, too," he says. "The reality is that until we have the opportunity and the time to give the kids the skills to learn, both how to basically function and to be more alert, the medi-

cine plays a role."

Summit has drawn state scrutiny, however, because of what DiMezza calls a "multifactor evaluation process" for admission. The schools have a psychologist and physician on staff, and administrators work with psychiatrists, licensed counselors, and social workers to evaluate students. The process, which resulted in a number of changes to students' special education classifications, helped Summit draw more money from the state—along with the ire of local districts.

In 2003, the Ohio Department of Education audited the schools' files. While errors were found, the state ultimately ruled that Summit had not overidentified students.

"I can pretty much guarantee that there has been more scrutiny over our process than any other school in Ohio," DiMezza says. "We had 12 professionals from the department of special education going through our files with a fine-tooth comb. Of course they found errors. You don't go through that many files and not find errors, but they also found that we were not creating the problems that some people said."

DiMezza says Summit is researching the connections between AD/HD and Asperger's as well as bipolar and other associated disorders. But ultimately, he believes, labels are not as important as results.

"The end result is the same. We find out what each particular child's needs are and fill those needs. What they are labeled is almost irrelevant to us. It is our job as educators to fill the needs of our children."—G.C.

noticed he lacked impulse control and had endless energy, often staying up until 3 or 4 a.m. Before he entered kindergarten, she decided to try medication.

"You have to look at this as a disease or condition that a child has," she says. "If a child has asthma, you buy him an inhaler and medication, and it can be taken care of. If a child was diabetic, you would give her the shot. My son needs it. For him to function and be OK in society, he has to have it."

Susan Garrison, principal of Lorton Station Elementary in Fairfax County, Va., says schools must respect parents' wishes regarding medication but let them know when an untreated child is performing poorly.

"We have to respect, and we do respect, parents' rights and their take on things, but we have to be advocates for the child as a learner and as a person," Garrison says. "There are times when we have to have reality meetings with the parents, and say to them, 'Your child is taking three times as long to learn the material as the other children. That's OK, but be prepared, because your child will not be as successful as he or she could be.'"

Garrison, whose school serves 935 children in grades pre-K through six, says elementary school can be difficult for the untreated AD/HD child because the classrooms are "unusually stimulating."

"AD/HD children can learn, but there are holes in their learning because their attention is focused elsewhere," she says. "Look around at any elementary school at the centers, the projects on the walls. These are necessary things for the normal learner, but they can overwhelm a child who has trouble focusing."

BEHAVIOR MANAGEMENT

Behavioral treatment, usually in combination with medication, is considered key in helping children with AD/HD. The treatment can include visits to a therapist and result in modifications both at home and in the classroom.

"There are some real behavioral things we have done," Dayna Miller says. "We do not do homework at nighttime. He just cannot handle it. We do it when the meds kick in and he's ready for school. Being in first

grade, this may not last forever, but for now that's what we have to do."

Since 1999, NIMH has sponsored what is considered the best known and most comprehensive study on treating AD/HD. The study, which is ongoing, has indicated that medication and behavioral treatment together are more effective than either one separately. In a 2004 follow-up study, students who stopped taking medication saw AD/HD symptoms return, but those who remained on the medication did not.

"Medication alone doesn't give them the skills they need to succeed, such as study skills," Quinn says. "But often, in order for the child to take advantage of what you're teaching, you need to use medication to deal with the basic problems of attention, concentration, and focus. You can talk about doing behavior management programs all day long, but it's often next to impossible if you don't combine it with medication treatment as well."

Once a child is diagnosed, parents can seek a Section 504 plan or an Individualized Education Plan (IEP). Both options, part of the often confusing legal maze schools and parents must navigate, require districts to provide modifications and services for the AD/HD child.

Ross, the CHADD executive, believes fervently that teacher training must be improved to help in the proper implementation of IEPs. As the father of a 14-year-old boy with AD/HD and other "co-occurring conditions," it's something he knows from personal experience.

"We had a very frustrating year with a physical education teacher who was in his first job, very young and without a lot of experience, who had stigmatizing attitudes about AD/HD and didn't know about the IEP," Ross says. "It took much of an entire year of us advocating for our son for this teacher to implement the IEP, and our son basically lost all of those months. I can't begin to tell you how frustrating it was."

WHAT SCHOOLS CAN DO

Despite limits on staff and resources, mental health professionals say school districts can do a lot to help children with AD/HD.

Adele Sebben, a retired Fairfax County

school psychologist now in private practice, says districts must provide more staff development for teachers.

"It's not just that you're going to have two or three kids with AD/HD," she says. "You're going to have all sorts of kids who are going to challenge boundaries. Teachers need to have help on an ongoing basis with these issues."

Quinn says schools must provide training to teachers on identifying symptoms as well as how the disorder affects boys and girls differently (see sidebar on page 29).

"Teachers are not that aware of the symptoms in general, but specifically how girls with AD/HD show the signs," Quinn says, citing the 2002 Feinstein Kean study that says only 11 percent of teachers felt they were well-trained in identifying signs of the disorder. "I think we have a long way to go, and school boards can help in this area."

So what should you do if your district doesn't have the money to pay for extensive staff development? Sebben says training videos are available, and teachers have regular faculty meetings that psychologists, counselors, and social workers can speak at throughout the year.

"I realize that it's difficult because you have so many demands on the curriculum with No Child Left Behind, but you have to make a commitment to talk about behavior issues," Sebben says. "You've got to get the behavior under control if you want to see the academics improve."

As a board member, Dayna Miller says parents with AD/HD children have approached her when they have had problems with a teacher or a particular school. She says she advises them to follow the chain of command.

"We had an incident this summer when another mother approached me about what to do," Miller says. "I told her where to go to access our board policies and said she needed to go back and talk with the teacher and principal about her issues. They needed to work together to find some good alternatives.

"And it worked. I've heard from her since then, and it sounds like they've gotten a lot of it worked out. That's progress."

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