

ASPERGER'S SYNDROME

often goes undetected. A parent's awareness can make all the difference.

Tyler Douglass, age 10. Right with his parents and strongest advocates, DeDe and David Douglass.

When A Child Can't Relate

B Y S H E R Y L F L A T O W

WHEN TYLER DOUGLASS was 18 months old, he was so articulate that people thought he might be gifted. But, as he grew, his mother saw a very different child.

"He was a hard kid to live with," says DeDe Douglass of Davis, Calif., a former special-ed teacher. "He had no social skills. He could talk and talk about whatever interested him, but he didn't make conversation. He'd think nothing of walking out when someone was talking to him. He would say the most inappropriate, insensitive things to people. He had no friends. He preferred to be alone with his toys, especially mechanical toys."

Tyler also was sensitive to light and sound, and he suffered from anxiety attacks and depression. He had no coordination and little physical strength. "No one could figure out why all this was happening," says Douglass. "I kept hearing that he was severely emotionally disturbed or that maybe my husband and I needed a parenting-skills class."

Then, when Tyler was 6, his parents brought him to the MIND (Medical Investigation of Neurodevelopmental Disorders) Institute, a research and treatment center at the University of California, Davis. There, he was diagnosed with Asperger's syndrome, a less severe form of autism, a condition in which children withdraw into their own worlds. Finally, Tyler's

parents could begin their search for proper treatment.

Asperger's syndrome is being diagnosed in greater numbers than ever before. But it is often misunderstood and misread, with the result that many children don't get the help they need.

What is Asperger's syndrome?

Hans Asperger, an Austrian pediatrician, first described the disorder that would come to bear his name in 1944, just a year after the psychiatrist Leo Kanner, working in the U.S., identified autism. But it wasn't until 1994 that the American Psychiatric Association recognized Asperger's in its *Diagnostic and Statistical Manual of Mental Disorders*. Some



"Tyler had no empathy and no friends," says his mother. "But he's come a long way."

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"They're frequently referred to as 'little professors,'" notes Marjorie Solomon, a researcher at the MIND Institute. "Their use of language is more formal or stilted than you would expect from children, and they can go on and on about a particular interest—like black holes or sharks—about which they know a lot of facts."

Researchers have not yet discovered what causes Asperger's. "There are a lot of theories," says Sally Ozonoff, a clinical psychologist at the institute. "We know that these traits absolutely can run in families. But what runs in families isn't just autism or Asperger's. The same genes appear to have different effects: You see speech disorders, language disorders, learning disabilities, social difficulties and loner siblings or parents. And there might be an environmental influence as well."

It is the lack of social skills that most sets children with Asperger's apart. That is certainly true of Andrew

Crain, a very bright 13-year-old also from Davis, who was diagnosed with Asperger's in 2000. "Andrew sees how kids at school interact, and he knows there are other forms of communication going on," says Carissa Crain, who began looking for answers when her son was 8. "He knows he misses things, and it makes him very frustrated and angry. He says he's not human, because he can't handle human emotions. He's had lots of behavioral problems in school, and we've had a hard time getting the school district to deal with Asperger's rather than focus on his behavior."

experts still question whether Asperger's is anything other than high-functioning autism. Others see clear distinctions between the two. "In autism, children appear to be born without an interest in others," says Ami Klin, Ph.D., an associate professor at the Yale Child Study Center in New Haven, Conn. "Children with Asperger's syndrome seem to crave relationships but don't know how to establish them. They simply don't

know how to interpret the cues that would be important for them to participate more meaningfully in social interactions. As a result, they tend to get into a lot of behavioral difficulties. They have limited self-censorship, so they may say whatever comes into their minds."

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Exploding numbers

The number of cases of autism in the U.S. has been skyrocketing. Until the 1980s, it was thought to be between one in 5000 and one in 1000, based on numerous studies; today, experts believe the figure is closer to one in 500. That's an increase of about 1000%. Some maintain that because specialists have become better at diagnosing autism, they are catching the borderline forms as well. One of the few studies on the incidence of Asperger's puts the number of cases at one in 1200. It is found four times more often in boys.

Getting children the help they need

While there is no cure for Asperger's, experts agree that the earlier a child is properly diagnosed and receives individualized assistance, the better the chance that he can lead a quality life. "Unless we intervene, the waste is too great," says Ami Klin of Yale. Some children with Asperger's also are treated with SSRIs, a type of antidepressant that helps control ritualized behavior.

Each specialist interviewed for this article agreed that it's generally best for a child with Asperger's to be "mainstreamed," but with additional help. "These children have a social disability, and they need to practice

PHOTOS BY BOB RIEBER/TYLER (LONGHORN), ANDREW (ANDREW) AND DREW (DREW) (YALE)

their skills in a natural environment," explains Klin. "But you can't just place them in regular schools and forget about them. The child needs to be provided with a continuum of services. For some things, they need to work in small groups. For others, they need individual attention."

Many children, however, are *not* getting the help they need. Andrew Crain, a voracious reader who can finish a 1000-page book in two days, was given no classroom

assistance or accommodation by his school system and failed just about all of his classes last year. "If you don't have the resources in place when your child is in elementary school, it's virtually impossible to get the services you need later on," says his mother.

On the other hand, Tyler Douglass, now 10, has an aide in his fourth-grade classroom, as he has had since first grade. He has had all kinds of therapy—at the MIND Institute, in school and in private. He's also on medication.

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DeDe Douglass is a tireless advocate on her son's behalf. "Tyler has come a long way in the last year and a half," she says. "He still has anxieties and phobias. His lack of empathy has been the toughest thing for me as a mother, but he is now developing some. After all the therapy, he's a little happier, less depressed. He's more tuned in to other people. He still tends to go off into his own world, and he's content to be by himself, but he also needs to be around people. He's started a bird club, which has given him friends for the first time.

"You've got to start somewhere. I just want him to be able to do what is socially appropriate—not just for other people but for his own dignity." ■

For more information on the signs of Asperger's syndrome and for a list of resources you can find on the Internet, visit www.parade.com on the Web.

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If You Think A Child Has Asperger's

The best hope for children with Asperger's syndrome is early diagnosis and intervention. But waiting lists for an appointment at major research centers can range from six months to two years or more. Here's what you can do:

- **ASK YOUR PEDIATRICIAN FOR A DEVELOPMENTAL EVALUATION,** says Ami Klin of Yale. "Birth-to-3 services, psychologists and speech psychologists can help identify problems. Intervention cannot wait."
- **WORK WITH THE SCHOOL** to establish an individual education plan for your child once you have a medical diagnosis. In some places, if the parents are dissatisfied with the school's response, they can pursue the matter legally.
- **GO ONLINE.** Experts stress that parents should look for other resources besides doctors and schools, noting the Internet in particular. Support groups provide the most up-to-date advice from professionals and parents who already have navigated the system in search of help.