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Lifestyle

Often-misdiagnosed syndrome creates special challenges for families



Facing Asperger's

By CARA NISSMAN

Brian Braudis' passion for baseball covers all bases. He sits entranced for hours, designing stadiums with intricate plans for the shops, entrances and dugouts. He grabs his glove and pitches to imaginary players. In conversation, Brian always reverts to the World Series, good games and accomplished players.

"It's kind of hard to stop," said Brian, 10, of Chelmsford, flanked in his room by his favorite baseball bat, caps and cards. "I still don't know who wants to talk about baseball and who doesn't."

One of the hallmarks of Brian's condition, Asperger syndrome, is an inability to read social cues, such as body language, that hint someone's grown tired of a particular subject.

About one in 500 Americans have some form of

Asperger syndrome, a neurobiological disorder that often is described as autism without mental retardation, according to the National Institute of Child Health and Mental Development. Symptoms can include difficulties with social interaction and communication; repetitive, odd interests or behavior patterns; and extreme sensitivity to physical sensations.

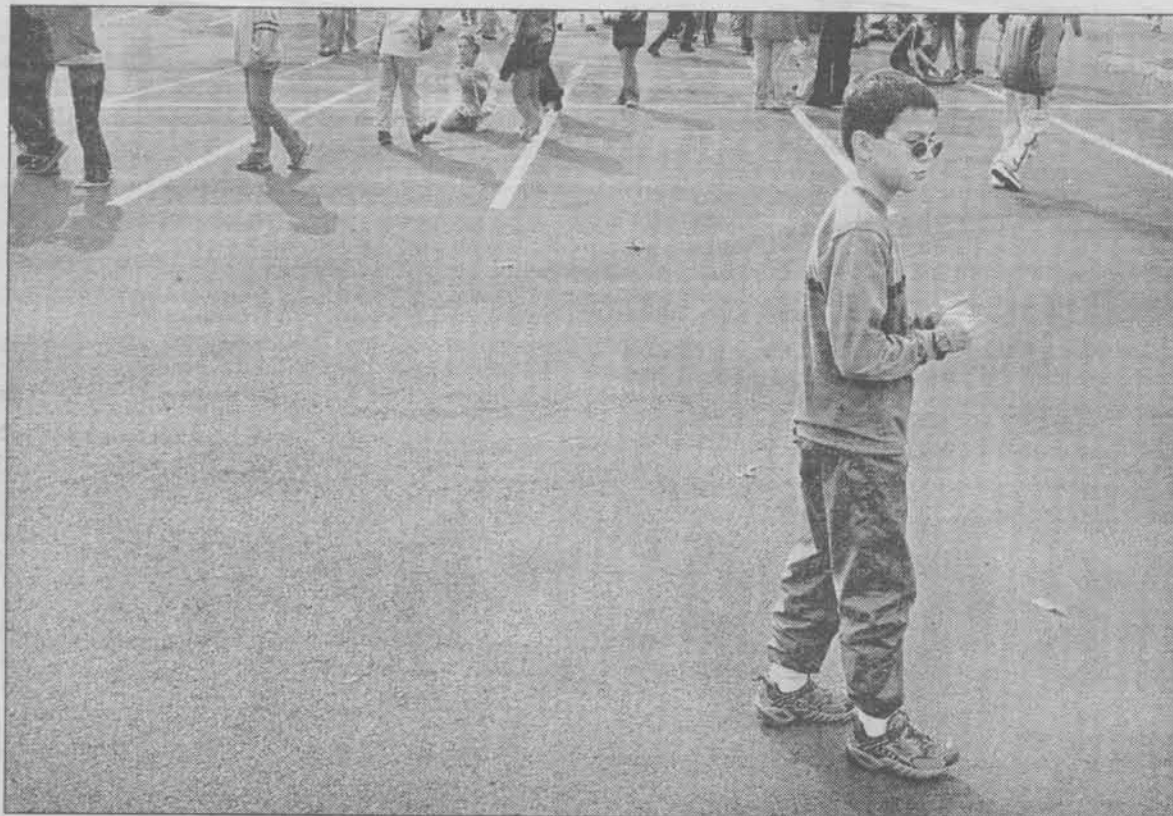
Although it's difficult to differentiate AS from high-functioning autism, children with AS are more likely than autistic kids to desire social connection.

"It's a myth that they don't want to be with others," said Dania Jekel, executive director of the Asperger's Association of New England, based in Newton. "They tend to be excluded because they don't know quite how to do it. They don't know what's appropriate to say and not say. We see a lot of depression in these kids

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STAFF PHOTO BY DAVID GOLDMAN
FUN TIMES: Brian Braudis, 10, breaks out in laughter. Brian has Asperger syndrome, a disorder similar to autism but without the mental retardation. Brian and his mom, Judy Steiner, share a light moment, above, in their Chelmsford apartment.



BETWEEN TWO WORLDS: Ten-year-old Brian Baudis of Chelmsford, who has the neurobiological disorder Asperger syndrome, tends to shy away from other students during recess. In small groups, however, he interacts much more readily. Below, Brian shares a laugh with a friend in his fifth-grade language arts class.

STAFF PHOTOS BY DAVID GOLDMAN



Parents help

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because they're lonely."

"I have trouble in groups," said Brian, who fidgeted with a toy horse to stay focused while he spoke. "There's another kid who collects baseball cards and I've asked him to trade cards with me."

Many AS kids also experience unusual responses to stimulation and the environment, said Dr. Michael D. Powers, author of the new book "Asperger Syndrome & Your Child: A Parent's Guide" (HarperResource, \$24.95). Fireworks and school bells or even a slight bump in the cafeteria line can be excruciating. Some AS kids seek rigidity, experiencing "meltdowns" or extreme tantrums when faced with minor changes in routine.

"It's also difficult for these kids to (infer) other people's perspectives and express emotions," said Debbie, a MetroWest mother of a 17-year-old girl with AS. "If she received a gift when she was younger and didn't like it, she would get up and throw it in the garbage can" in front of the gift giver. "You can't say, 'Honey, you should know better,' because they often don't get it."

More awareness among doctors, educators and parents and better diagnostic methods have translated

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DANIA JEKEL, EXECUTIVE DIRECTOR OF THE ASPERGER'S ASSOCIATION OF NEW ENGLAND

into an increase in AS diagnoses in the past few years.

"I'm getting 15 to 30 calls and e-mails a day, and most of them are related to children," Jekel said. "When I first started the association 10 years ago, the youngest child diagnosed was 3 or 4. Now they're 18 months old because people are noticing symptoms and traits much earlier."

Yet similar symptoms can occur in people with other psychological and developmental disorders.

"There have been people who have been misdiagnosed before they've been identified as having AS," said Powers. "Some kids might have seemed like they had obses-

Learning about Asperger

If you've recently learned your child has Asperger syndrome, investigate the following for guidance and support:

Books

- Echo R. Fling and Tony Atwood's "Eating an Artichoke: A Mother's Perspective on Asperger Syndrome" (Jessica Kingsley, \$19.95, 2000).
- Ten-year-old Kenneth Hall's "Asperger's Syndrome, the Universe and Everything" (Jessica Kingsley, \$14.95, 2001).
- Kathy Hoopmann's fantasy novels "Blue Bottle Mystery: An Asperger Adventure" (Jessica Kingsley, \$11.95, 2001) and "Of Mice and Aliens: An Asperger Adventure" (Jessica Kingsley, \$11.95, 2001).
- Dr. Teresa Bolick's "Asperger Syndrome and Adolescence: Helping Preteens and Teens

Get Ready for the Real World" (Fair Winds, \$24.95, 2001).

- Brenda Smith Myles and Diane Adreon's "Asperger Syndrome and Adolescence: Practical Solutions for School Success" (Autism Asperger, \$23.95, 2001).

Organizations

- **Online Asperger Syndrome Information and Support** at www.udel.edu/bkirby/asperger.
- **The Asperger's Association of New England** in Newton at 617-527-2894 or www.aane.org.
- **The Asperger Syndrome Coalition of the U.S.** at 866-4-ASPRGR or www.asperger.org.

— CARA NISSMAN

kids with syndrome reach out

sive-compulsive disorder or attention deficit disorder but then the person actually has Asperger's."

Although there is no cure for AS, psychiatric counseling can help those with the condition to become aware of their actions and better function within society.

But parents have to be advocates for their children, Powers said. AS kids tend to excel in hands-on settings, so parents should discuss the condition with their child's school officials and create an individual education plan that emphasizes projects over essays. Parents can ask that the school notify their child before any big changes in routine, such as a fire drill.

"You have to be prepared when you walk into meetings," said Brian's mom, Judy Steiner. "I keep all these binders with reports and correspondence. When you walk in with binders, they won't even try to snow you."

Telling family and friends also can help AS kids adjust.

"Self-acceptance and family acceptance is a huge part of healing," said Dr. Sally Ozonoff, co-author of "A Parent's Guide to Asperger Syndrome and High-Functioning Autism: How to Meet the Challenges and Help Your Child Thrive" (Guilford, \$35). "Thanksgiving's not a good time to do it but you can bring it up another time," when a relative notices a peculiar trait.

AS kids must decide whether to tell their peers.

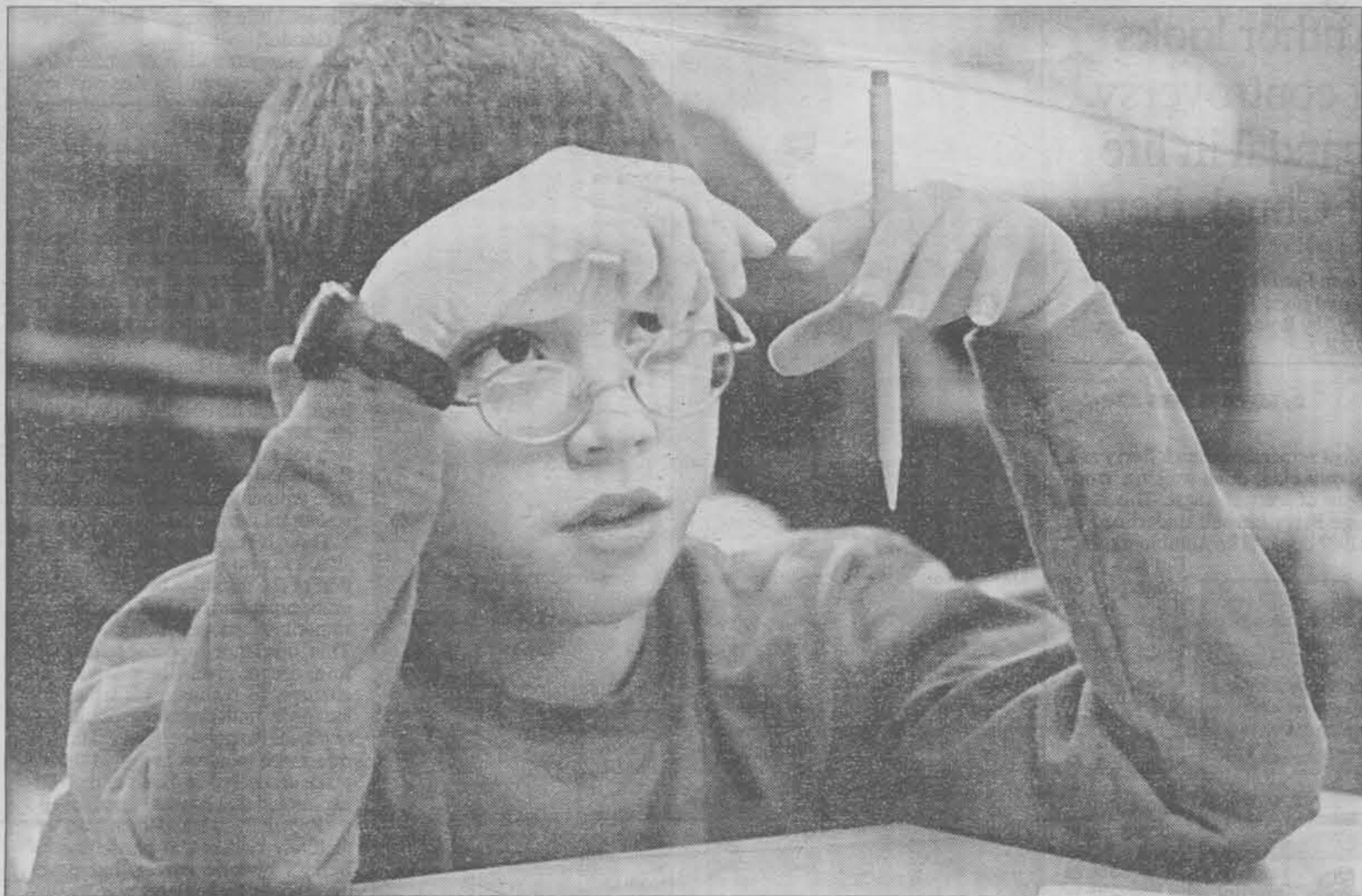
"I don't normally tell people I have AS," Brian said. "I don't want to explain it because I don't really understand it."

Powers said despite their difficulties, most of these children can thrive as adults.

"I tell parents that if an adult with Asperger Syndrome is not gainfully employed, somebody messed up," he said. "It all comes down to finding the right job to fit the right person."

"One of my patients was fabulous with numbers and the best job he ever worked at was with a rental car company, checking if charges had been applied correctly. He worked by himself and worked within his needs."

"These kids really have a passion and conviction about something early on, so in terms of finding a career or niche in life, we know where



INNER FOCUS: Brian is distracted momentarily during class. Because of its similarity to attention deficit disorder and obsessive-compulsive disorder, Asperger syndrome is often misdiagnosed. Right, avid baseball fan Brian claps as Cal Ripkin Jr. is introduced at the start of Game 4 of this year's World Series. Developmental experts say children with AS discover at an early age the things that will become lifelong interests.

to go," Ozonoff said. "They know what lights their fire before many other kids, even college students."

Janet, a Cambridge resident, has a 19-year-old daughter with AS who attends a small, out-of-state women's college. Her daughter always has liked sea creatures and plans to draw on that in the future, she said.

"She's doing so well that she hates being considered anything other than a normal kid," Janet said. "The small college is good for her. There's not too much social stuff going on. She can study marine biology and be

successful. She'll be an incredible researcher."

Brian said he wants to be a baseball player when he grows up. His mother said he'll more likely work as a statistician or sports analyst if he can continue to learn to adapt to the world around him.

"You can't change children with AS. You can only help them adapt," Steiner said. "It's challenging, but I wouldn't change who Brian is. He is very much a joy."

"(AS) has you redefining what's important in life. We can learn a lot from AS kids."

