

Understanding Asperger's: Invisible disability

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By DONYA ARIAS

THE CAFETERIA at Margaret Brent Elementary School in North Stafford is a lively and raucous place, echoing with the loud chatter of kids enjoying each other's company, if not the food.

But on a recent afternoon, 11-year-old Cory Fore sat quietly and stared down at his lunch of a breaded chicken sandwich, yellow corn kernels and chocolate milk. The boy next to Cory smiled and chewed heartily, but the two might as well have been sitting at separate tables. Cory contemplated his lunch tray as if it were a complex puzzle, ignoring the boy beside him.

Often seemingly in a world of his own even in the midst of lunchroom chaos, Cory, 11, has Asperger's syndrome. The condition, also known as high-functioning autism, is linked to normal to high intelligence but difficulty with social and communication skills.

While Cory has a great chance of growing into an independent adult, his prospects for holding down a steady job, making friends and settling down to married life are slimmer than average because of what his school psychologist calls Cory's "invisible disability."

A mystery revealed

His mother had a nagging feeling something was wrong when Cory wasn't speaking by age 2. Billie Bailey said if she'd been a more experienced mom, she "would have known something was up sooner."

After a screening by Spotsylvania County child development specialists, Cory qualified for and began speech therapy. One therapist noticed that Cory had lax ligaments, or floppiness in his feet and ankles, and the muscle tone in his mouth seemed "off." It was an early clue, but nothing came of that observation. A neurologist's exam also was inconclusive.

Meanwhile, Cory struggled to get along in day care, had no respect for authority and was described by his teachers as "bouncing off the walls." When he was 4, a psychiatrist suspected Cory had attention deficit hyperactivity disorder. Bailey didn't buy that diagnosis and refused to put Cory on Ritalin, thinking he was too young for the medication.

The final straw came when Cory was expelled from first grade for bad behavior within weeks of the start of the school year. An exasperated Bailey took her son to see Fredericksburg pediatrician Dr. Allen Aaronson, who watched Cory for a few minutes in an exam room and said he suspected an "atypical autism presentation." In other words, Cory fell somewhere along the spectrum of autistic behaviors that affect an estimated one in 166 American children.

Autistic behaviors can run the gamut from extreme to mild, from constant head-banging and an inability to speak to daily struggles with understanding how to get along with others.

"I stress that it's a spectrum," said Aaronson, who marvels at the progress Cory has made in the past few years thanks to diligence by his mom in getting her son treatment. "I rarely see Cory, because he's never sick."

When Cory does come to the office, Aaronson sees a child who communicates, looks him in the eye and behaves pretty much like a typical 11-year-old boy.

And in many ways, Cory is typical. He's a healthy-looking boy with close-cropped, light brown hair and a fondness for baggy shorts and soft T-shirts. He recently went on a weekend camp-out with his Boy Scout troop, a trip that seemed more nerve-wracking for his mother-left worrying at home-than for Cory, who now proudly displays his Scout patches on a yellow sash in his bedroom.

Cory is doing well in school academically. Yet he seldom is invited to birthday parties, and when friends come over to his house to play, the encounters often end in tears or a shouted argument. Child's play, for a kid with Asperger's, simply does not come naturally.

Like many with his condition, Cory likes to stick to a routine and can come unglued when hungry, tired or unfamiliar with his surroundings. He can revert to hitting his mother or sister, or screaming. That often leads to stares at restaurants, or snide comments made just loud enough for Bailey to overhear what a bad job she's doing by not disciplining her son.

"I've had neighbors not want to meet us because they heard about my son," said Bailey, who lives in a quiet Stafford County neighborhood along a gravel road off Poplar Road. "That really hurts."

More than just 'quirky'

The average age for an autism diagnosis is 2. For Asperger's, it's 6, probably because the syndrome's symptoms are more subtle and don't necessarily involve a speech delay. That later-age diagnosis makes the situation sticky, because early identification of autism-spectrum disorders is considered invaluable to treatment.

First defined by physicist Hans Asperger in 1944, Asperger's syndrome was added to the American Psychiatric Association's Diagnostic Manual in 1994. The manual characterizes the syndrome as "qualitative impairment in social interaction" that can be accompanied by a lack of facial expressions, a failure to make friends and such habits as repetitive behavior.

People with Asperger's often have "a circumscribed area of interest which usually leaves no space for more age-appropriate, common interests," psychiatrist Dr. R. Kaan Ozbayrak wrote on a Web site describing children with Asperger's.

Barbara Birsinger, who founded the Online Asperger's Information and Support Web site after her son was diagnosed at age 8, wants people to know Asperger's is a neurobiological disorder, not a behavior problem. "It's not just about being a little 'quirky,' and it's most certainly not about being a bad child or a bad parent," Birsinger said. "Children are often misunderstood by their peers, their teachers and society as a whole."

For Cory, the disorder shows when he repeats the phrase "I like eggs" throughout an entire school day, or shoves a classmate so he can be first in line. He almost always is riled by one particular girl, a 13-year-old neighbor who comes over to play regularly and ends up in slugfests with Cory.

In a weekly group session with the school's psychologist and speech pathologist recently, Cory sat politely at a table with four other boys, listening intently to what everyone was saying. He didn't often speak up, answering questions in a quiet voice and hiding his mouth behind his hands.

"He pretty much wants to melt into the chair," said Amy Pawlak, the speech pathologist at Margaret Brent Elementary.

"I do worry about what middle school will be like, because kids are mean."

Early intervention

The earliest possible diagnosis and intervention are critical to giving kids with Asperger's and other autism disorders their best shot at reaching their potential.

"The earlier the diagnosis, the better the outcome," said Nancy Wiseman, author of "Could It Be Autism? A Parent's Guide to the First Signs and Next Steps."

Wiseman is the founder of First Signs Inc., a nonprofit group that advocates for early diagnosis and intervention for children with developmental delays. Her daughter, Sarah, was diagnosed with autism at age 2, and the 10-year-old is now excelling in schoolwork, aspires to be a professional figure skater and is more social than many girls her age because of early treatment, Wiseman said.

"I had to do whatever I could that was going to improve the outcome for my daughter," Wiseman said. "Nobody was going to tell me she wasn't going to college."

Autism treatment is controversial, with different camps championing different types of intense therapies. Sometimes the goal is for a child to be "mainstreamed" to fit in as normally as possible with peers. Other techniques emphasize each child's unique abilities to respond to others and learn to appreciate emotions. Many children, including Cory, take medications to ease anxiety.

Whatever the treatment method, child advocates seem unanimous in their support for the earliest possible treatment.

Walter, of Northern Virginia, who asked that his full name not be used because Asperger's "carries a bit of a stigma," helps lead a D.C.-area support group for adults with the syndrome. He wasn't diagnosed until seven years ago, at age 36. He said he likes to hear about children such as Cory, who were diagnosed and had access to treatments at an early age.

"I was a bit of the egghead who couldn't relate to my peers," Walter said of himself as a child. He said he wanted to talk about presidential elections in minute detail, while his schoolmates were more interested in sports.

"Growing up, I was told by my parents, who didn't know any better, that I was lazy," Walter said. "It was just harder for me to do things."

School psychologist Robert Haxter said his goal for Cory in middle school is to bond with one friend. "He's never going to be comfortable in a crowd," Haxter said.

Heartening progress

A lack of close friendships doesn't seem to bother Cory at this point, even if his parents and teachers worry. Among his favorite pastimes: cooking (his specialties are pizza and mac 'n' cheese), riding the family horses, playing with his pet rabbit, reading and drawing.

On a recent afternoon at his house, Cory happily snacked on cubed watermelon with his 6-year-old sister, then wandered his front yard in search of honeysuckle blossoms.

When his stepfather parked his car in the driveway, Cory wandered over, Popsicle in hand, and plopped down in the front seat. The key was in the ignition, with the front door ajar and a chime sounding.

"Cory, don't sit in Dan's car," his mother ordered. Cory ignored her.

"Cory, out of the car," she said again, firmly. Cory stared forward, feet on the pavement, eyes fixed on the windshield. As soon as Bailey turned her back, Cory stepped out of the

car and walked into the garage, strapping on a pair of inline skates, disaster averted for now.

"The hardest part was not knowing," Bailey said about Cory's behavior before the Asperger's diagnosis.

Since then, Bailey is heartened by Cory's progress (though like many parents she can spend the day praying for the arrival of bedtime). She's convinced he will grow up to be an independent adult. In the meantime, she could do with fewer angry stares at the grocery store or in restaurants.

"My goal would be just to educate people about Asperger's," Bailey said, "so my son doesn't get asked to leave people's houses and gets invited to birthday parties."

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