

Three families try to cope with Asperger syndrome

by Scott Hilyard

Erika Banina grimaced as she attempted an immobilizing grip on her son Jonathan, who thrashed on her lap fighting against both the unwelcome restraint and whatever demons inhabit his mysteriously wired brain.

"No, mommy, no, mommy, no, mommy, no, mommy," Jonathan, who is 4, screamed repeatedly. "Why? Why? Why?"

Erika cried softly - almost imperceptibly - and blew out an attempt at a calming breath as she held on with all her strength.

The reason for her son's over-the-top tantrum?

A teeth cleaning at the dentist's office, which to Jonathan was an assault on his delicate senses. And he suffers from Asperger syndrome.

"I dread these appointments," said a drained Erika afterward.

LIFE WITH ASPERGER™S - Erika Banina of Peoria, Ill., grimaces while holding on to her 4-year-old son Jonathan as he kicks and screams at the top of his lungs during a dental cleaning appointment. Erika tries to limit how often she takes him out in public as similar breakdowns have occurred in public shopping centers. CNS Photo by David Zentz. Jonathan had stopped writhing on his mom's lap and was happily accepting the good-boy praise of the dental technicians as he decided what treat to select from a bag filled with lots of options. He settled on the rubbery hand that sticks to walls and glass surfaces while Erika pinched the bridge of her nose between her thumb and forefinger after wiping away her tears.

"I'm going to go home and try to recover," she said.

Jonathan is the son of Erika and Chris Banina of Peoria, Ill. Named after Jonathan Davis, the lead singer of the heavy metal band Korn, Jonathan Banina is usually in constant motion despite the twice-daily dose of the mood stabilizing drug Depakote. At 4, he flies solo through all his favorite sites and games on the Internet. His mother, who suspects he has taught himself to read, calls Jonathan "mysterious and awesome."

Asperger syndrome is defined as a less debilitating form of autism. However, those with it are faced with difficult challenges.

Among other emotional and mental disorders, Jonathan's Asperger syndrome is generally considered less debilitating than the more familiar and severe form of autism where children become lost in a world that's disconnected from everyday life. That it's less debilitating is not, of course, the same as saying that living with Asperger's is like owning a lifelong pass to a family amusement park.

The syndrome, often bewildering in its manifestation inside the mind and behavior of a child, comes complete with its own set of challenges, stressors, heartaches and joys. "It is a challenge," said Lisa Bowe, who is an autism consultant with the Special Education Association of Peoria County, and whose son, Michael, 12, has Asperger syndrome. "The kids look normal and usually have average or above average intelligence, but they typically are kind of quirky and have trouble fitting in socially. Think back in high school and the kid with the polyester pants and pocket protector carrying the briefcase down the hall. We just thought he was a geek. There's probably a good chance there was a little bit of Asperger in him."

First identified and named as a neurological disorder in the 1940s, it was for decades thought to be relatively rare and caused by lousy parenting. Its cause is still not known, although theories about genetic and environmental connections have supplanted the notion that unloving parents can create a child with autism. Now one child in every 166 births in this country lands somewhere on the broad autism spectrum, totalling as many as 1 million to 1.5 million Americans with autism, according to the Autism Society of America. What percentage of those are people with Asperger syndrome is unknown. There are also countless people who are undiagnosed.

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Emily Davis, 14, looks like a typical high school freshman - jeans, white shirt, funky vest, lime green Chuck Taylor high tops. When she gets home from school each day she heads straight for the TV room, where she pops in a Japanese anime cartoon and starts reciting the dialogue and singing the songs whether it's in English or Japanese and whether she has seen that particular videotape once or 100 times. Her dad, Gary Davis, is divorced and has custody of Emily and her brother, Adam, who is 12 and has profound autism. All the time, really, though out in public particularly, Emily is endearingly protective of her brother, who by society's standards of normalcy can act pretty crazy.

Recently, Emily fumbled with the key to the front door, got it open with some help from her grandmother, Sue Davis, and then disappeared through the portal that separates the living room from the TV room in her small Peoria Heights home.

She slid a copy of "Dragonball Z" into the VCR next to the TV and immediately started reciting lines in advance of the characters saying them. She had taped the program off Cartoon Network two days before and knew the whole program like a sixth-grader knows the Pledge of Allegiance.

That is to say, cold.

"See that dragon? He can grant three wishes," she said, standing 2 feet away from the TV, seemingly immersed in the stiffly animated, brilliantly colorful, wildly fantastic parallel universe of Japanese anime.

The commentary kept coming. The smile on her face seemed to widen as the tape rolled.

"That's the Dead Souls check-in station. I know it's weird, but I get the point."

"The dead people come up out of the ground and sit on their gravestones."

"Hey, you're in the wrong movie. Get out of here."

"Oh, crud, it's Freeza."

And then, from nowhere:

"I'm a girl who always memorizes things."

Emily's language skills developed slowly as a toddler. And then, at age 4, she had Disney's "Little Mermaid" movie memorized after two viewings.

"She'd sing all the songs and act it out seconds before the characters, and we thought, 'Boy, that's neat,' " he said. "Little did we know at the time ..."

In high school, Emily takes regular classes and one vocational class. Her grandmother drives her to school in the morning because of some unpleasant bus stop experiences in the past, and her father typically picks her up. The routine doesn't vary much. At the end of the school day, she moves back into Anime Land.

"That's her world. It's where she's comfortable, and it's what she knows," said Emily's grandmother. "When I hear her in there laughing and getting involved in her programs it just warms my heart."

Gary Davis sounds almost more concerned about Emily's future than Adam's, whose profound autism has him locked in a world known only to him. Adam frequently "zooms," a family description of his zooming through the house like he's imitating flight. In his first hour home after a day in a special needs classroom in Bartonville, Ill., he clings to his father, smelling his hair.

"Adam will live with me until I die or I can't take care of him anymore," Gary Davis said. "Emily, I don't know for sure. I'm trying to stay open-minded about it. She might be able to live on her own or in some group setting or something. She continually surprises me with what she's able to accomplish, but she still behaves below her age level."

Grandma Davis picked Emily up on a recent half-day of school. She drove her to Best Buy. Emily had a list of anime discs she was interested in, and wanted to see what she could afford.

She stood in front of the anime section and pulled disc cases out, studied them, made notations on her list and replaced the case. Ten minutes later, she was done.

"OK," she told her grandmother. "We can go now."

No purchase. No begging for a purchase. No begging for money for help with a purchase.

"I think I have enough money to get "King of Bandit Jing," she said when she reached the parking lot. "It's \$29.99."

She paused at the van door.

"I'll tell Dad," she said, and stepped into the van.

Lisa and Joe Bowe's son Michael Bowe, who is 12 and a sixth-grader, wants to print and sell T-shirts that read, "I Have Asperger's Syndrome: What's Your Problem?" He is also the author of "Asperger's Syndrome 4 Dummies," an unpublished book with acknowledged copyright issues because of its copycat title, where he tries to explain what's it's like to live with the disorder.

"I am writing this book because I am tired of people, much like my father, not understanding me," the book begins. "I have a lot of trouble with things like noises, handwriting, changes in schedules, motor skills and social skills."

On a recent day, Brimfield School District Superintendent Dennis McNamara left Michael Bowe's individual education plan meeting to go fetch Michael Bowe from a room where he was doing his homework.

All the others at the conference table - therapists, teachers, consultants, psychologist, social worker, parents - remained at the table but one. She stood up to create a seat for Michael next to his father, Joe Bowe, who himself stood up and moved so that Michael could sit next to his mother.

"I know better," Joe Bowe said.

Michael entered and sat down next to his mother, Lisa Bowe.

"Well, Michael," McNamara began when everyone was seated. "You're doing well. Your grades are average to above average."

"And if it ain't broke, don't fix it," said Jane Rosenbohm, Michael's literature teacher.

And with that, Michael Bowe was no longer a "special needs" student. There would be no more individual education plan meetings to determine how a team of educators and professionals could best help Michael reach his educational goals.

But he still has Asperger syndrome.

And that meant he still has his dad to please.

"I was totally clueless for a long while," Joe Bowe said. "The behavior issues made me angry and there were times I thought we had a spoiled, selfish little mama's boy on our hands. I walked away many times. I'm convinced it's why God wanted me to have a pond. I'd grab my fishing pole and go."

Joe Bowe is more enlightened now than he was in the confusing years before Asperger's helped explain some of Michael's odd behaviors - the meltdowns, the clumsiness and the pickiness about everything from the clothes he wears to the foods he eats.

"We just recently got him out of the soft wind pants and into blue jeans," Lisa Bowe said.

"Blue jeans are hard to fasten," Michael Bowe said. "But I guess I need to start liking them."

Michael Bowe's new routine this school year - he's in sixth grade - is to walk to the town library after school, work on his homework and wait for his mom to pick him up. When he gets home he goes to the basement and bounces a rubber ball off the floor for an hour. Or two. Or more.

"It's a stress reliever," said Lisa Bowe, who leads an autism support group once a month at Easter Seals in Peoria. "He has to work so hard all day long to keep it together that he needs some sort of activity at the end of the day. He used to jump from the couch to the day bed for an hour or two."

Michael is sound sensitive. The sound of his younger sister's voice can drive him to irrational anger. A classmate crumpling up a piece of paper can drive him to distraction. He despises sudden changes in his schedule and is obsessed with even numbers and numbers divided by five. For instance, if Michael has control of the TV remote, the volume control number will end on a 0, 2, 4, 5, 6, or 8. No odd numbers.

Why?

"I don't know," he said. "I have no control over the rules my brain makes."

Michael is drawn to television programs that feature smart women who speak their minds - "Golden Girls," "Roseanne," and "I Love Lucy" are among his favorites.

"It's because he blurts stuff out himself," Lisa Bowe said. "He can relate."

In his book, "Asperger's 4 Dummies," Michael offers some insight into the Asperger's brain.

"So the next time you are with somebody with Asperger's syndrome, you should treat them like you do everybody else, but remember the things that they have problems with: noise, touch, handwriting, body language, multitasking, schedule changes. Now you know what things to do and what not to do. And this is my first book on Asperger's syndrome."

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One day last July, before medications became a daily part of his life, Jonathan Banina leaped headfirst from the arm of the living room sofa into the coffee table in front of it.

"There was blood everywhere. I was totally petrified," Erika Banina said. "We thought he had a concussion and a broken nose at least. Then when we got him to the emergency room I look at him and I'm thinking, 'Why isn't he crying?' Here he was all beat up and the only thing he was complaining about was the hospital gown was too scratchy."

Jonathan has issues beyond Asperger syndrome. While he's probably too young for doctors to come to mental health conclusions, he is likely battling bipolar and obsessive-compulsive disorders on top of his autism. But elements of his behavior are classic Asperger's.

"He doesn't really talk like a kid," Erika Banina said. "Out of a bunch of mumbling and gibberish will come a sentence like, 'Oh, what a wonderful surprise,' or, 'That's an excellent idea.' He doesn't model the speech of

other kids, he models the speech of adults."

Sensory sensitivity is another common symptom of Asperger syndrome. One weekday last September, Erika Banina loaded Jonathan into his car seat in the back seat of her car and drove to Hines School for his scheduled speech, occupational and physical therapies. His usual therapy room was being used for testing, so Jonathan's sessions were moved to a room on the other side of the school. To get there he had to cut across the gym, which at the time was also the cafeteria. It was lunchtime. High-pitched grade school chatter rattled off the hard walls and high ceiling inside the echoey gym.

Jonathan stepped through the door, heard the noise and shot his mother a hard-to-define look. Terror? Make these kids shut up? How could you do this to me?

He walked the length of the gym with his hands clasped firmly over his ears.

Jonathan is also sensitive to light ("It's impossible to get him to sleep. We have these blue rope lights around his bed; that makes it look like a spaceship. It's calming," Erika Banina said), and he has sensitive skin. He resists getting his hair washed and his nails trimmed. He is obsessed with all things "Thomas, the Tank Engine," - videos, toys and games.

The disorder affects nearly every aspect of the Baninas' life. Erika worked in a dental lab up until a year ago, but freaked out, in her words, from the stresses building at home one day and never returned to work. Chris Banina now works two jobs to make up the deficit, frequently for 14 to 16 hours a day.

"And because I think he sometimes prefers the time spent outside of the house," Erika Banina said.

Household finances are tight, medical coverage uncertain and his future is unknown as he approaches his school-age years. In recent weeks Jonathan's medications have begun to fail him, and some of his more violent, unpredictable behavior has returned. Doctors are working to find the right combination and dose.

"Friends watch Jonathan on the computer and say, 'Oh, my God, your kid's a genius,' " Erika Banina said. "A genius who can't put on his own shoes. We're trying. It's physically taxing on me and the house and emotionally taxing on the marriage and it ages you twice as fast, but we're trying."

Jonathan, who had been occupied with a puzzle on the living room floor, stood up and shot out of the room like he suddenly realized he was very, very late for an important appointment.

"What kid moves that fast?" Erika Banina said.

And then she stood up to go look for him.

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