MARTINSVILLE BULLETIN

Autism: Growing challenge
'It's time that people learn about it' — mother

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(This is the first article in a series on autism. The series will look at aspects ranging from the issue facing parents and school to legislative issues surrounding insurance coverage.)

Emily Mullen, 5, who has autism, plays with her mother, Sharon Mullen, in a classroom at Clearview Early Learning Center in Martinsville. (Bulletin photo by Kim Barto)

Sharon Mullen wears a T-shirt that reads “1 in 150 American children” on the front.

The back of the shirt says, “If 1 in 150 American children were being kidnapped, we would have a national emergency. WE DO. It’s autism.”

Mullen, who lives in the Carver area, wants to increase awareness about the neurological disorder that affects her 5-year-old daughter, Emily. Her T-shirt reflects the growing number of children diagnosed with autism.

Autism is a complex developmental disability that affects the normal functioning of the brain, impairing a person’s ability to communicate and interact with other people.

No two people with autism have the exact same symptoms, and they range from mild to disabling. There is no cure, only therapies that, when started at a young age, can help a child reach his or her full potential.

Evidence is everywhere that the disorder is becoming more widespread. The waiting lists to see autism specialists in Richmond and Charlottesville are several months long. This year, the New College Institute and Averett University both launched series of classes to help teachers and school administrators educate students with autism. Legislation was presented to a state House subcommittee last week that would have mandated health insurance coverage for certain autism treatments.

But although the Centers for Disease Control and Prevention report that more and more cases of autism spectrum disorders are being recognized, public awareness has yet to catch up. Mullen and other parents say they face constant misunderstandings about their children who have autism and the daily challenges that face them.

“Most people just don’t understand, and I think it’s time that people learn about it,” Mullen said.

EARLY SIGNS

From day one, Sharon Mullen knew Emily was different.

When her son, Wesley, was born, he cried all the time. But when Emily arrived two years later, she was quiet and did not cry much.

“I thought maybe it was just a difference between boys and girls,” Mullen said, but then other red flags appeared.

“When she started sitting up, I’d say something to her, and she’d keep playing like she didn’t hear me,” she said. “She wasn’t making any sounds.”

Thinking it could be a hearing problem, a doctor checked Emily’s hearing and eyesight when she was 18 months old, but the diagnosis turned out to be a developmental delay.

The family was living in Texas at the time. At age 2, Emily was referred to the school system there and set up with a speech therapist. Meanwhile, a committee of 12 people from different disciplines assessed her for autism.

“She was in this big room playing as people walked around taking notes. We met with a speech therapist, speech pathologist, did hearing tests,” Mullen said.

“I kept thinking, ‘How many of these assessments do we have to do before we know what’s going on?’” she said. “I was just kind of spinning around, not knowing what to do.”

When doctors told Mullen her daughter showed nine out of 10 signs of an autism spectrum disorder, “I was kind of relieved,” she said. “A lot of people are devastated (at the diagnosis), but I never went through that.”

Children with autism often keep the “developmentally delayed” label until age 9, and although doctors at the University of Virginia confirmed Emily has autism, her diagnosis has not officially been changed to reflect this. Her school Individual Education Plan (IEP) classifies her as “developmentally disabled — speech and language delay,” her mother said, and so far this has entitled her to get the services she needs.

The reality of Emily’s delay hit Mullen after a conversation with a therapist.

“I felt encouraged when all of a sudden she (Emily) said ‘dog’ one day,” Mullen said, but at that point, Emily was almost 3 years old and should have been speaking in sentences.

“The speech pathologist sat me down one day and told me, ‘You need to get a grip on where your child is now, instead of just assuming she’ll wake up one day and start talking,’” Mullen said.

Mullen realized then, “I need to switch my thinking around,” and immediately started intervention services for her daughter. Mullen met with the school to discuss Emily’s IEP, and the child began preschool four days later.

With autism spectrum disorders, it is critical to start treatment as soon as possible, experts say. The earlier a child can be diagnosed and begin therapies, the better chance they have of joining a regular classroom later on.

EDUCATING AN AUTISTIC CHILD

In Texas, Emily was in a class of 29 preschoolers, a mix of special-needs and typically developing children. She was in that class for one year before the family moved back to Henry County in June 2007 “to get family support,” said Mullen.

Emily then began attending Clearview Early Childhood Center, where she is one of two developmentally delayed preschool students in the Martinsville Schools. Each has an individual teacher.

Now in her third year in a school setting, Emily’s speech has improved. She can say about 75 words and just started spelling her name in the past few weeks. She recently started regular speech and occupational therapy, and the therapists come to the school to work with her.

But improvement comes and goes, her mother said.

“When school’s out, she regresses and doesn’t talk for a while,” Mullen said.

The characteristics of Emily’s autism do not hold true for all people on the autism spectrum. In her case, she can be social “to a point,” her mother said, sometimes playing with another child but generally ignoring anyone she does not like.

Emily also has a nightly ritual of “stimming,” where “she picks up little tiny objects, holds them up to her face and has conversations with them” for about 45 minutes before going to bed, Mullen said. “She’s rewinding through the day. I can’t interrupt her, or she’ll start over.”

Many children with autism have sensory issues: they can be hypersensitive to certain textures or foods, and some do not like to be touched. Emily is sensitive to scratchy fabrics and tags in her shirts, “so when I buy a shirt, I cut the tags out and wash it four or five times before she can wear it,” her mother said.

However, except when she’s upset, Emily is “pretty affectionate” and gives hugs, she added.

At home, “I just kind of do what I can” to help Emily, Mullen said.

In the past, she bought a Picture Exchange Communication System (PECS) book and vocabulary flashcards for Emily to use and taught her some sign language “as a last resort when she wasn’t speaking,” Mullen said.

To teach her more vocabulary, “I walk around naming things all the time,” she said, emphasizing words like “Now we’re going to put on our blue jeans and yellow shirt.”

Sharon Bushnell, case manager for the Piedmont Regional Infant/Parent Program at PCS, said Emily is “a very bright little girl, very high-functioning.”

As for her mother, “Sharon is one of those parents we love to work with,” Bushnell said. “She wants to be in the know, educates herself and is a very strong advocate for her daughter. You have to be, because no one else will do it for you.”

“PARENTS ARE OUR BEST ADVOCATES”

Parents can make a big difference for their children with autism.

Last year, a high-functioning Martinsville student with autism graduated with an advanced high school diploma and went on to community college, said city schools Special Education Director Paulette Simington.

“He’s very intelligent; he just has to make minor modifications” in the classroom, Simington said. His fellow students “really helped him feel comfortable and to fit in.”

But a major factor was the help of his parents, “who have been his advocates from day one,” she said. “His parents were persistent, did research” and made sure he got the therapies and services he needed.

“They didn’t allow him to be secluded” and “worked with him at home on social communication,” Simington said.
It was Simington who “helped me get into my advocacy,” Mullen said, by asking her to serve on the school Special Education Advisory Committee.

“I thought, I have to be the voice for autism here,” Mullen said.

Parents of special-needs children sometimes ask her for advice, and Mullen wanted to make sure she gave them the right information. She started taking a training class through www.wrightslaw.com, a special education law and advocacy site for children with disabilities. Mullen recently began the self-paced CD-ROM and book and plans to finish the advocacy training in a few weeks.

“It’s parents who are persistent who get the services they need,” said Jeanne Westphalen, educational diagnostician and special education instructional coordinator for Martinsville Schools. “Parents are our best advocates.”

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