



Girls' autism signs miss early diagnosis

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The Journal Gazette

There's nothing unusual about Emily Disher. Not at first glance, anyway.

In many ways, the Fort Wayne 12-year-old is a typical sixth-grader. She does her homework. She plays with her Wii (probably more than her parents wish she would). And, of course, she worries. Usually about ordinary stuff. Grades, friends, fitting in.

But spend a little more time with Emily, and you begin to notice there is something different about her.

She stands a little too close, for instance. If she's looked at for too long, she gets angry. And when she is excited or happy, she rocks – rhythmically bending back and forth and repeatedly putting her hand to her lips and yanking it away again.

"Emily's struggles are social," her mother Angie Disher says. "If you met my daughter, unless you spent a day or two around her, you wouldn't know anything is wrong with her, except she's a little odd."

In 2001, Emily was diagnosed with Pervasive Developmental Disorder, Not Otherwise Specified, or PDDNOS, a condition on the autism spectrum in which some – but not all – of the features of autism are present. The diagnosis took the Dishers two years – and countless visits, evaluations and observations by doctors – to receive. At the time, the family lived in Muncie.

"No one could see it," Disher says. "Emily met all her milestones, but I knew something was wrong. The doctors, the school, all they saw was a hint of this and a hint of that. It was a late diagnosis, but I was almost relieved when it happened."

Autism – and disorders, like Emily's, on the autism spectrum – is generally considered a boy's health issue, in part because it's nearly four times more likely in boys than in girls, according to the Centers for Disease Control. Of the 560,000 people younger than 21 who have autism in the United States, only about 140,000 are girls – a small group – which makes data and research about autism in girls (and whether or not autism manifests itself differently in boys and girls) pretty scant.

One thing, however, is apparent. On average, girls are diagnosed with autism later than boys, says Renee Buskirk, special education specialist for Fort Wayne Community Schools.

Frequently, girls are not diagnosed until middle or high school, when social nuances become more complicated. Until then, girls with disorders on the autism spectrum are often perceived as just being shy, Buskirk says.

"Before middle school, a girl's symptoms may be masked, in part, because of how girls are socialized in our society," she says. "We raise them to avoid outward behaviors like aggression. Instead, they're quiet and polite. It's only later that we notice it goes beyond shyness. That these girls are not picking up on teenage girl talk. That they're becoming socially isolated."

This was the case with Maureen Johnson, 37, who was diagnosed with PDDNOS only two years ago.

Johnson, an assistant professor of public health at Indiana State University in Terre Haute, was surprised by her diagnosis, she says. "It shocked me, honestly," she says. "I tried to deny it at first, tried to argue that I didn't have it."

Looking back, the signs were all there, she says. Her sensitivity to noise and light, for instance. Her lack of eye contact. And even as a college student, she continued to walk on her tiptoes like a toddler. "In most of the pictures of me as a child, I'm crying," Johnson says. "Because the flash from the camera would physically hurt my eyes. And that's one of those pervasive things you don't outgrow when you have an autism spectrum disorder. For instance, right now I'm on the phone with you in my office and I have the lights off. I'm still really sensitive to light."

Johnson's sensitivity to light and sound – along with her other symptoms, such as an inability to pick up on certain social cues – were written off as "odd behavior" when she was younger. But during the 1970s and '80s, autism was not a diagnosis people looked for, especially in girls, she says.

"I'd guess there are a lot of people born before 1990 who are being misdiagnosed or not diagnosed at all," she says. "If a girl is quiet, if she's not disruptive and has more subtle symptoms, she's less likely to be taken to a doctor. That's how I wasn't noticed. I got good grades. I was never taken to the principal's office. I often wonder how things would be different if I'd have been diagnosed at 3. If it would've helped or hindered me."

Generally, early detection and intervention is preferred, for both boys and girls, Buskirk says.

When a human enters the teenage years, the neural networks of the brain becomes less plastic and altering brain development becomes more difficult. Which means girls who are diagnosed later are not given as much opportunity to learn social coping skills. "From a practical point of view, a late diagnosis provides less opportunity to build into a daily schedule the time it takes to teach and learn social skills," Buskirk says. "In middle and high school, students become more interested in academics. We try to do the best we can, but there are only so many minutes in a (school) day." Autism in girls does not always go unnoticed. Early detection happens frequently in cases of classic autism, where symptoms are the same in boys and girls.

Local mother Lisa Breit had no difficulty finding a diagnosis for two of her daughters, Raleigh and Piper Singleton. The two girls exhibited all of the classic symptoms – loss of language, lack of eye contact, rocking and head banging, sensitivity to light and sound. What Breit can't find are answers to her questions. For instance, how will her daughters' autism be affected by the physical changes they will face during puberty?

"I'm terrified," she says. "Raleigh is going to flip out."

Recently, Breit heard a friend talking about how her own traditionally functioning 11-year-old daughter was getting ready to begin menstruating for the first time. Raleigh is 6 and Piper is 3, but





Sonnenberg Consultants

March

2009



menstruation was an issue Breit had not had time to think about before then, she says.

"It scared me," Breit says. "I don't know how other parents have dealt with that because I've never heard anyone talk about it. If there's a pill that would allow Rileigh to not menstruate at all, I'd be interested in it. But then, you think, that couldn't possibly be healthy for her, right? There are just a lot of unanswered questions."

hear from many people who want to honor their neighbors, classmates, or others affected by autism in their community by giving back. 1Power4Autism gives people a very powerful tool to really engage with their community to help ASA improve the lives of all affected by autism."



The site also features event ideas from people who have already taken up the cause, like John Lose and his Rock the Boat for Autism Team, who are rowing from Boca Raton, Fla., to Wildwood, N.J., this summer to support ASA, or Missy Lybrand, who started Harley-Davidson Ticket to Ride in her Jacksonville, Fla., community that has grown by leaps and bounds over the years.

The Autism Society of America today launched its "1Power4Autism" campaign, a public awareness and fundraising effort that will, through an interactive Web tool, enable everyone to make a difference in the lives of those affected by autism. As the nation's largest grassroots autism organization, ASA hopes the new tool will create a "power grid" of communities across the country that can join together to help others during National Autism Awareness Month this April.

Turn on your power today - visit <http://www.1power4autism.org/>!

1Power4Autism is the first grassroots fundraising Web site for the autism community. It gives people an opportunity to "turn on their power" by starting an event online and then using ASA's Web platform to register and recruit their friends and family. Anyone can walk, run, race, golf, cycle or row for autism - the possibilities are endless and the potential for engagement limitless. For those who would like to support autism through joining events, 1Power also allows people to search for and support other events already being organized in their community. The tool also harnesses the power of the Internet to spread awareness of the condition, which now affects 1 in every 150 people in America today.

Company updates: (WI families)

- Please mark on your timesheet, at the end of the month if you completed all your scheduled shifts.
- All shifts need to be made up one on one with the client, it can't be made up with another therapist present.
- All tutors need to go to their original shifts first - there is no switching for another house no matter the reason.

"The Autism Society of America recognizes the power that one person, one organization, one idea or one event can have on autism," said ASA President and CEO Lee Grossman. "We





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- If you want extra hours please contact your senior

Joke of the Day

A man and a dog were going down the street. The man rode, yet walked. What was the dog's name?

Answer: Yet

