

# Deciphering the Puzzle Life with Autism

By Kristen A. Graham

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As the number of children diagnosed with autism continues to increase, more and more families must learn to deal with its effects.

# **“What can we do to help them? Where can we go? What is autism, anyway?”**

**— Mary Edmison '87**

**S**ix months in 2006 changed Mary (Stevenson) Edmison's life. During that span, her two toddlers — first Owen, then Grace — were diagnosed as autistic. The news sent Edmison '87 (B.S.) and her husband, Steve, reeling.

Autism is a developmental disorder often characterized by impaired social interaction, problems with verbal and nonverbal communication, and unusual, repetitive or limited activities and interests. Autistic children might display attachments to unusual objects, hypersensitivity to different senses, difficulty with transitions, stereotypic behaviors such as rocking and hand flapping, and lack of engagement and awareness of group activities. It is not known what causes autism — some speculate immunizations and mercury are to blame, though no clear evidence exists — and though interventions can be helpful, there is no known cure. Some children are born delayed, but many develop normally and begin regressing around the age of one or two.

According to the Centers for Disease Control, one in 150 children in America today has an autism spectrum disorder; it is the fastest-growing developmental disorder in the country. Every minutes, a child is diagnosed with autism. The Autism Society of America estimates that 1.5 million Americans and their families are affected, calling the disorder “a national health crisis, costing the United States at least \$35 billion annually.” Experts believe that an increasing awareness of autism, coupled with environmental and genetic factors, help account for the booming rate of the disorder.

Autism disorders are prevalent, costly — and often devastating to families, with an 80 percent divorce rate for parents of autistic children, according to the National Autism Association.

For the Edmisons, who live in rural New Mexico, 60 miles away from the nearest town, services were tough to come by. And, of course, there was the children's behavior. Owen, now 5, was obsessed with the moving parts on his toys. Grace, now 3, was fixated on stick-like things. Owen, in particular, was impossible to control — he was so locked into routine that if they turned left instead of right out of the driveway, he would melt down.

“I looked like a deer in headlights,” Mary Edmison recalls of those early days. “I was just so frazzled. Owen was a little tornado — you couldn't get him to sit down. It was like



*Owen, Steve, Mary '87 and Grace Edmison*

destruction was everywhere in his path.” Edmison managed to get Owen into a program run by the local school district and Grace into a state-sponsored program because she was under 2 at the time. “That's when we started going full force into, ‘What can we do to help them? Where can we go? What is autism, anyway?’” remembers Edmison.

She consulted with a pediatrician who advocated a biomedical approach. Removing milk and wheat from the children's diet and putting them on a vitamin therapy program — multivitamins with a high B concentration, omega 3 fish oil — did wonders for them, she says. Suddenly, the little boy whose eyes wandered all over the room while you spoke to him met your gaze.

“Within three months, both of their eye contact improved,” says Edmison. “Owen's stomach problems went away. Their eczema got better.”

In the old days, Owen had trouble concentrating for 30 seconds; now he can stay on task for 30 minutes. He'll sit in his chair and follow routines. At the time she was diagnosed, Grace wasn't using even the simplest phrases. Now her vocabulary encompasses more than 100 words, and physical therapy is helping her weak muscle tone. And though issues remain — Grace will only eat about 10 different foods, Owen's sensory issues mean fingernail and hair cutting are torture — Edmison chooses to think about the progress they've made.



Michelle Rowe, Ph.D., professor and director of interdisciplinary health services at Saint Joseph's, researches how families cope with autism. Rowe, who has family members affected by the disorder and whose background is in biopsychology — the science of how the brain affects behavior — notes that autism is a particularly puzzling condition.

"People affected by autism are like snowflakes — no two are alike," she says. Those who are autistic are often referred to as being "on the spectrum" — the autistic spectrum ranges from Asperger's to PDD-NOS (Pervasive Developmental Disorder-Not Otherwise Specified), a catchall diagnosis for those who do not fit into another category of autism. Often, children might have the same diagnosis but very different issues. Some children are very social, and others are incredibly withdrawn. Some have tremendous cognitive skills, and others do not.

Though information about autism abounds, what parents really want, Rowe says, is practical, nuts-and-bolts details: how can you entertain without disrupting your son's routine too much?

"It's a roller coaster," Edmison says. "In the beginning, it was a lot of tears and frustration. There are still tears and frustration, but I try to focus on how far they've come."

She also finds that serving as an activist, not just for Owen and Grace but for all autistic kids, helps her cope with the enormity of her job as a parent. "Part of my therapy is advocating for Owen and Gracie," explains Edmison. "I find out what they need, and if it's not available, I fight to make it available. These school districts might not be the experts. They may never have dealt with a kid like yours."

Edmison has battled with her local school district to make sure the kids' IEPs — individual education plans — include all the services they need. When the district said it did not have adequate speech language services for Owen and Grace, Edmison located the services — 60 miles away, at New Mexico State University — and now she drives them twice a week, every week. Edmison has lobbied the legislature for more funding for autism services, started a local support group for parents of autistic kids, attended national autism conferences and even won recognition from the legislature for her efforts. Helping other parents is a joy, she says.

"If I can do anything to answer a question or help someone find services," she offers, "that's great for me. I was so isolated for so long — I didn't know anyone with autism. But I'm a doer. I want to help."

Jessica Lovinsky's experiences with autism were altering. Growing up with an autistic friend spurred Lovinsky '03 (B.S.), '04 (M.A.), to pursue a career helping others — especially those with autism. When Lovinsky was 10, she began helping her best friend babysit the friend's little brother. Beginning at about 18 months old, the boy would cry until he held his breath and passed out. Nothing would soothe him. Doctors thought he was hearing impaired for a short time but soon diagnosed him as autistic. The word never frightened her, she says.

"The first thing I knew was a child, not a label," she recalls. "I knew I loved that little boy. He was like family to me, and then I started to learn about autism. As a result of growing up and adoring this child, I have such an understanding of it."

Fifteen years ago, autism wasn't as well-known or accepted, and Lovinsky remembers battling for acceptance of the little boy. "People would stare at him and say, 'What's wrong with him?'" she says. "Having other people in the community accept him was hard. It was important that he have play dates with other children, and that was tough."

Now, the boy is thriving, mainstreamed in high school. He interacts with autistic classmates and is living a happy life. "He still has very stereotypical autistic behaviors," she acknowledges, "but because he had such early intervention, he has made amazing progress. He makes me proud."

How can you manage an outing to the grocery store with your disruptive daughter? There are potential solutions, she points out — some businesses are sensitive to the needs of autistic kids. Disney World, for instance, permits parents of autistic children to skip waiting in long lines.

“A lot of it is preparing — if you have a family party to go to, you give your child as much advance preparation as possible so they can handle the sensory issues,” she says. “You bring an iPod because your child really likes music, and if it looks like he’s going to melt down, you take him to a quiet room. You walk away from family members who are not helping you cope.”

Rowe, who is conducting research about parental strategies for coping with autism, also teaches a Service-Learning class where students learn about the disorder through working with autistic children. “The philosophy behind it is there’s no way students can learn about autism unless they see it,” says Rowe. Students go to schools and private institutions; they see close up that autism does not affect one socioeconomic group or ethnicity. “The students are really enthusiastic about their Service-Learning experience,” she says. The class typically attracts students majoring in education, psychology and health services, and is kept small, with about 15 students.

For the past five years, Rowe has sought to increase understanding

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**— Michelle Rowe, Ph.D.**

of the complex condition by bringing experts to campus for an annual panel discussion on the subject. April is Autism Awareness Month, and Rowe hopes to break down barriers.

“People think everyone who has autism is like Rainman, that all they do is watch *Jeopardy* and *Judge Wapner* and memorize things,” observes Rowe. “They see stereotypes.”

With the increasing prevalence of the diagnosis, though, most people now know someone who is autistic. And what often gets lost is the progress that has been made. Early interventions — which happen when the brain is in one of its most critical periods of development — can be enormously useful in helping autistic children reach their full potential. And there is plenty of support out there. Parents of autistic children are “such a strong network,” Rowe says. “They’re an incredibly caring, supportive group of people and so knowledgeable in terms of understanding the disorder. They know what it’s like, and they want to help others.”

He has also shaped her career path. When Lovinsky arrived at Saint Joseph’s, she saw an advertisement for a discrete trial teacher working with a three-year-old autistic child. Lovinsky’s interest was piqued, and she took the job, working with the little boy at his home for three hours a day. They worked on social interaction, on elementary learning concepts such as shapes and colors, and on helping the boy use his words to communicate. Lovinsky would shadow him at preschool and encourage him to interact with other students.

“The goal was just to have the other children appreciate him for who he is, and that happened,” she says. “The kids learned that he was a fun little boy, not just an autistic little boy.”

Lovinsky says the sense of joy she took from that experience was unparalleled. “It just made me feel so good,” she says. “I’m helping others to see what I see in these children. It’s a matter of diversity. It’s really rewarding for me to help children see that other children may appear different, but they’re just like them.”

These days, Lovinsky is finishing up her certification as a school psychologist, working as an intern at a school and at the Children’s Hospital of Philadelphia. Her dream? To work in an elementary school, helping all kinds of children — especially those with special needs.

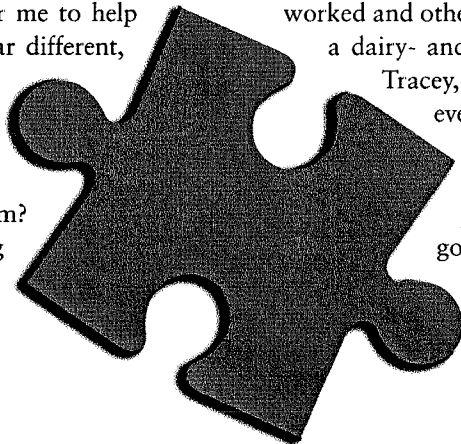
**R**ob Cola ’97 (M.B.A.) vividly remembers a conversation he had with a coworker years ago. “He told me about the struggles his family had with autism. I remember thinking, ‘How do they do it?’” When his youngest son was diagnosed five years ago, he found out.

“It’s a constant struggle, and you have to be vigilant and active,” he notes. “There’s nobody out there to tell you what to do — there’s a ton of stuff out there on the Internet, but no manual.”

He recalls the day of Jason’s diagnosis at the Children’s Hospital of Philadelphia as “the day that my life — all of our lives, the whole family’s — changed forever.” Jason, now 6, is a smart little boy but has some behavioral issues. He gets distracted easily; loud noise overwhelms him.

After Jason’s diagnosis at age 20 months, Cola and his wife Tracey set up services for their son, but found that some things worked and others didn’t. They, too, have found supplements and a dairy- and gluten-free diet helpful for Jason. That means

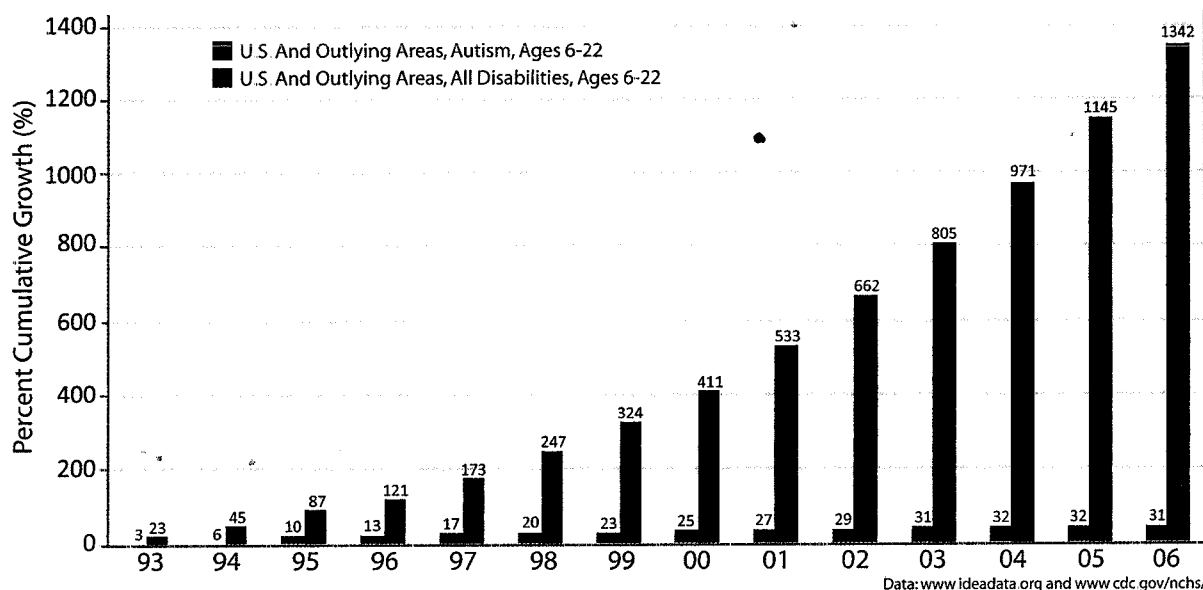
Tracey, who mail orders or makes from scratch nearly everything Jason eats, often makes two separate meals, one for Jason and one for everyone else. And the special dietary needs make restaurant meals problematic. “We can’t just pick up the family and go out to eat,” Cola says. When they discovered recently that Maggiano’s, a local chain restaurant, makes gluten-free pasta, it was a banner day.





# Autism on the Rise

Number of Cases / Cumulative Growth  
(U.S. School Years 1993-2006)



This chart shows the cumulative growth rate of the number of children ages 6-22 with autism from 1993 to 2006 in the United States and outlying areas, compared to all disabilities, including autism. The data show a 1,342 percent cumulative growth rate of autism over that time period.

Cola worries about the effect of Jason's needs on their other children, Eric, 11, and Lauren, 9, but he's glad that Jason has a big brother and sister to look up to. "I don't think he'd be where he is without the other two," says Cola.

He considers himself lucky — the family has the means for Tracey to stay home full-time with the children and being Jason's advocate has become her job. The Colas have already fought numerous battles with their school district and county intermediate unit, the agency responsible for early childhood services for special needs students.

Finding a school that's a good fit for Jason has been a real struggle. He's now on his fourth school, a pricy private institution the family is paying for out-of-pocket. But it's not a long-term solution: Cola believes he'll have to move the family in order to find a better public school district for Jason. For families of autistic children, it's a common dilemma. "We'll pick where we live based on the school district, how good the special-ed services are," he says.

Despite the challenges of living with an autistic child, Cola sounds like any other proud dad when he talks about Jason. "He's a funny kid — he goofs around and makes jokes," he laughs. "If you spent five minutes with him, you might not know anything was wrong with him." But Cola is sure of one thing. "When you have a child who has autism," he says, "autism permeates all aspects of your life."

The following Web sites are among many that may provide more information for families coping with autism:

[www.autism-society.org](http://www.autism-society.org)

[www.childbrain.com](http://www.childbrain.com)

[www.jhsph.edu/cadde](http://www.jhsph.edu/cadde)

[www.kennedykrieger.org](http://www.kennedykrieger.org)

**“It just seemed if we could understand the cause, we could change it.”**

**— Todd Moody, Ph.D.**

**T**odd Moody, Ph.D., appreciates that sentiment. His son Dylan was diagnosed with autism at the age of 3 — after a frustrating year of Dylan’s speech regressing and doctors waving off the concerns of Moody, a Saint Joseph’s professor of philosophy, and his wife.

The couple’s emotions ranged from anger to fear. They worried that they had done something wrong; they researched everything they could find on the disorder.

“It just seemed if we could understand the cause, we could change it,” Moody remembers.

In those early days of Dylan’s diagnosis, a time Moody refers to as “the hellish years,” the family isolated itself. Dylan acted out at times, displaying disruptive or eccentric behavior. He didn’t communicate effectively until he was 5. “You don’t have guests to your home under those circumstances, when you have a child whose behavior you just can’t predict,” says Moody. “You don’t go out places, you don’t go to other people’s homes or you don’t bring him. You just can’t relax.” Moody and his wife also worried about autism’s affect on their daughter, who is seven years older than Dylan.

Perhaps the toughest thing about Dylan’s autism was the cloud it cast on his future. “With typically developing kids, you think at least you know roughly what the future’s going to look like,” says Moody. “With autistic kids, there’s a curtain there, and you can’t see past it. We had no idea whether our son would speak normally, and no one could tell us. Nobody could promise us that.”

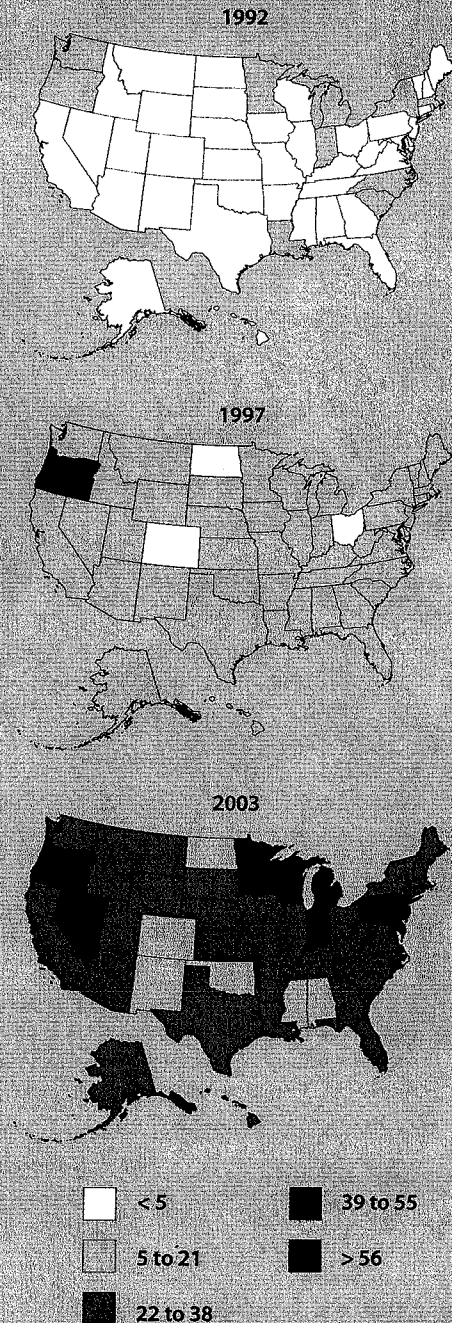
More than a decade after Dylan’s diagnosis, there are new challenges for the Moodys. Now 16, Dylan attends high school with some special education support. He has good language skills but still has some gaps in reading comprehension. And math has long been a struggle for him.

Now that Dylan is older, Moody and his wife are grappling with a new, thorny problem: how do they explain his disorder to their son? When they told him he was autistic, Dylan balked. “He certainly sees that he’s different in some way that prevents him from being readily accepted by kids his own age,” says Moody, “but he doesn’t talk about it, and he doesn’t know what it is.” He remembers when he was younger and rarely spoke, but says he was just shy. An acting workshop for autistic teenagers wasn’t his thing, but Dylan, who enjoys art, video games and his dog, was receptive to watching YouTube videos of other autistic people talking about their differences. “He could see that people were at all different levels, and some of them he could relate to,” says Moody.

These days, Moody and his wife watch their son and wonder what’s next for him. “Is Dylan going to live independently? How’s that going to work? Is he going to have a job? What kind of job?” The curtain is still there. But now, he says, “It’s gauzier.” ♦

*Kristen Graham is a Philadelphia Inquirer reporter.*

### Autism’s Trend Among U.S. Youth Individuals with Disabilities Education Act 1992, 1997, 2003



Units: Ages 7 to 9 per 10,000 births

Source: Public Schools Autism Prevalence Report Series, 1992-2003, [www.FightingAutism.org](http://www.FightingAutism.org), 2004.