



July 25, 2005

## Life with an out-of-sync child

Perseverance helps mothers find support, therapy and education for autistic children

*BY MARIA SONNENBERG*

*FOR FLORIDA TODAY*

The revelation came to Julie Graziano Mertens while chatting with close friends, all mothers of toddler sons. When one woman encouraged her child to show off a newly learned skill, the others chimed in, too, proud of their children's accomplishments. Mertens did not ask her son, Jamie, to join the fun. "What can Jamie do?" wondered Mertens to herself at the time. "He can't do anything," was the sad reply to her own question.

Mertens' 4-year-old son has autism, a developmental disorder that, according to the Centers for Disease Control and Prevention, affects as many as one of every 250 births. This neurological disability inhibits normal development of communication and social interaction skills.

On his first birthday, Jamie was a happy, loving toddler, perhaps even a little more advanced than some of his peers. He rolled, he stood up, he walked, he knew a few words. "I loved to show him off," said Mertens. During the next few weeks, however, the toddler Mertens knew ceased to exist. Jamie not only stopped progressing, he actually started regressing. "He wouldn't speak, he'd cry all the time and didn't want to make eye contact," said Mertens. It was at that moment that Mertens and her husband, Paul, entered the world of parents with a special-needs child, a painfully intense parallel universe unimaginable to anyone but to those who have been there.

### **Emotions on a roller coaster**

"When he started to regress, it was as if he wasn't my child anymore," said Mertens. "You're alone with your thoughts and a child you thought you knew. You're frustrated, confused, full of despair." Her friends, she found out, couldn't understand her plight. "My girlfriends would complain that their children didn't shut up all day," Mertens said. "All I wanted was my child to talk to me."

Instead, all Jamie could do was lash out and cry in frustration at his inability to communicate. Mertens remembers Jamie crying and screaming constantly on a car trip. "Many times, I'd just have to pull off to the side of the road," she said.

In the emotional roller coaster that is life with a special-needs child, parents become consumed with searching for possible solutions and for the resources that may make the solutions possible. "We're in a different system," said Jamie Barr, director of the Pre-K Program at the Space Coast Early Intervention Center. "It is life-altering, lifelong."

Barr's son, Ian, was diagnosed as autistic when he was 2 1/2 years old. Ian is 14 now and doing well at a Montessori Charter School in Cocoa, but the past dozen years have been a long, bumpy ride for Barr and her family. "I thought God would never give me a child with special needs because I was too self-centered," Barr said. "I was working in publishing, traveling quite a bit and also had a daughter."

As a marketing consultant for a textbook publisher, Barr was constantly on the go, visiting customers throughout the United States. After Ian's diagnosis, Barr quit her job to become her child's advocate for services, navigating the murky waters of available resources. At the suggestion of a psychologist, the family even left Pennsylvania for

Florida so Ian could spend more time outside. In a few years, Barr's marriage disintegrated and she found herself a single parent.

### **Navigating the stress**

"The rate of divorce for couples with disabled children is much higher," Barr said. "Mom has to quit her job and find resources, Dad has to take on additional jobs and the two are totally stressed." "It is stressful to find the appropriate services," said David Wilder, associate professor at Florida Tech's School of Psychology, who counsels families of children with special needs.

It also is expensive. "It's a financial burden," Barr said. "Some medical insurance will pay for some forms of treatment; others won't." There are more than 14,000 people on the waiting list for the state's Agency for Persons with Disabilities, which serves people with autism, mental retardation, spina bifida and cerebral palsy. The length of the list often translates into three years of waiting before money for services becomes available, a particularly tragic state of affairs because early intervention can be beneficial to many children with special needs.

When Jamie was first diagnosed with autism, the Mertens searched for a treatment method that would help him. They spent three weeks at the Spectrum Center in Bethesda, Md. They tried diet therapy, which required the purchase of special foods -- including \$6.99 loaves of bread -- online. "You grasp at straws until you find something that works," she said. For the Mertens, it was Applied Behavior Analysis, a treatment method that was proved extremely helpful in Jamie's case. Unfortunately, it is an expensive proposition to pay for the 20 or so hours a week the intensive therapy requires.

### **Bearing the burden of medical costs**

Because their medical insurance doesn't cover the expense, Paul Mertens must work out of state in a job that pays enough to cover the services of the Florida Tech psychologists who work daily with Jamie at the Mertens' Melbourne home. "There are so many sacrifices you have to make to pay for this kind of therapy," Julie Mertens said. "It's very tough for my husband and for me." Yet because early intervention is often crucial for a child with special needs, families typically will do anything in their power to obtain it. "We've worked with a lot of families who have broken up as a direct result of the financial strain of caring for a child with special needs," Wilder said.

Barr, a great believer in early intervention, became her own self-contained mini-agency to manage her son's therapy. She read every book on autism she could find. She posted flyers around town to hire college students to provide aspects of a therapy regime recommended by her doctor.

"As the child gets older, it gets more difficult," Barr said. "You want to try to keep the gap from getting larger." And with disabilities like autism, even the commonplace can become big obstacles. "You can't even find babysitting," said Barr. "Even with sports, a lot of coaches don't know how to handle children with developmental delays." Constantly consumed by the child's needs, the parents often fail care for themselves.

"The amount of supervision a child with disabilities needs never decreases," Florida Tech's Wilder said. "We see a lot of parents become very emotional. A lot of time they need a break." "If you don't have the support system, the networking, you can't make it," Barr said. "You're constantly exhausted." But for a parent of a child with special needs, when the victories arrive, they are that much sweeter.

Julie Mertens is awestruck by how far her son has advanced with the help of applied behavioral analysis. "He's improved 120 percent," she said. "ABA saved my son." Jamie is scheduled to enter a public pre-school next year, a far cry from the angry, unresponsive child he was less than two years ago.

To Julie Mertens, the day Jamie starts school will make all the sacrifices, all the tears, worth it.