

*“Living with Autism” for Sandestin Living Magazine*

By Sallie Boyles

Like most proud parents, John and Heather Boswell are delighted to discuss their children’s latest accomplishments. Emma, who is eight, already lives and breathes gymnastics as a strong competitor. JR, her ten-year-old brother, demonstrates a passion for karate as he prepares for his first-degree black belt test. Their busy school, extracurricular and social calendars create a hectic pace, but Heather, a fulltime mom, and John, one of Sandestin’s respected home builders, seem to have everything under control. From the outside looking in, this family appears to be among the fortunate with only minor worries in life.

Appearances can be misleading. JR is autistic, and attending to his needs demands heavy commitments of time and money that will continue for years. From obtaining the clinical diagnosis to researching answers, the journey has been scary, frustrating and all-consuming. Consequently, while agreeing wholeheartedly that they are exceedingly blessed with excellent professional resources in Destin, loving support of their extended family and friends, and two super kids, the Boswells’ daily challenges are significant.

They are further concerned about countless others who lack the same critical resources. Autistic awareness has grown, but the comprehensive regimens that such children require can be cost-prohibitive—if those programs are, in fact, available. Destin has exceptional services, but that’s not the case everywhere.

Even for those, like JR, who have a personalized game plan in place, the emotional and financial stress on families can be overwhelming. Approximately six children in 1,000 have an autism spectrum disorder, according to the National Institutes of Health, and the rates appear to be increasing. Reasons for autism point to genetic factors, but environmental causes are also indicated. Focusing on what to do next rather than on why it happened to JR, the Boswells hope to ignite new levels of awareness that lead to greater access of the educational tools and medical care that can tackle autism early and prepare children for adulthood.

The Boswell’s journey began like a small-town fairytale. Growing up in Fort Walton Beach, Heather and John knew one another through Choctawhatchee High School and their families. Running his own residential construction company, Heather’s father subcontracted Boswell Builders to frame houses that he was building, and John was among the crew.

“My dad began taking me to jobsites when I was knee high,” says John, “so I learned the business through the school of hard knocks.”

Heather, in turn, would visit her father’s construction sites, so it was simply a matter of time before she spotted her future husband on a roof and liked what she saw. Evidently, the attraction was mutual. “John no longer saw me as my brother’s little sister,” says Heather. They married in 1999.

With a two-year degree in Construction, John went to work fulltime for his father, Johnny. Heather, who majored in Criminal Justice and minored in Psychology, pursued a career as case manager for adults with psychological disorders. Both were eager for parenthood, however, so Heather resigned from her stressful job with the goal of getting pregnant. JR came along within the year. As the firstborn son and first Boswell grandchild, he assumed a special place in the family.

For the first year or so, JR seemed perfectly normal, but an ages and stages evaluation indicated that the toddler was behind in his development. “Heather noticed that he didn’t talk much,” says John, “but I was shy as a kid and thought he was the same. I went through a denial stage.”

Beyond being notably quiet, JR did not bond easily with others. Besides his mother, the only other strong attachment he formed was with one of his grandfathers—Johnny Boswell, or Pops.

“Ever since he was small, he migrated to me,” Johnny says. “If we were together at a large family gathering, JR would make his way through the crowd to sit on my lap.” Jokingly, he adds, “I just thought that meant he was smarter than the other kids!” Johnny, of course, makes it clear that all of their grandchildren are dear to him and their doting grandmother, Paula. Ryan, the middle Boswell son and the designer in the business, has two children—Dalton, seven, and Crimsyn, two—plus a baby on the way. Soon to leave the military and join the family company, Jared, Paula and Johnny’s youngest son, is not yet married.

As for JR, he evidently relates to his grandfather’s calm demeanor. “He can get next to me, and we can have a quiet conversation,” explains Johnny. “We are pretty much joined at the hip.”

Notably reserved but sweet-natured, JR never displayed the disruptive behaviors that are often associated with autism or other social/cognitive disorders. Nevertheless, Heather knew in her heart that something wasn’t right. When John wouldn’t admit the possibility of a problem, Heather went to her father-in-law. “She asked if something was wrong with JR, and I said yes,” Johnny recalls. “Heather and I recognized it early on, but John took several years to deal with it.”

Describing himself as someone who takes a commonsense approach to life, Johnny says he was inclined to face his grandchild’s issues, but he has compassion for his son and other parents who are reluctant to address deep fears and underlying disappointments. “JR was supposed to be the starting quarterback like his dad,” Johnny says, explaining that the painful reality for him and his wife, Paula, was watching John grapple with the unknown: Would JR live independently? Would he marry and have children? Would he find a suitable career?

“He was five-and-a-half when I acknowledged there was something different about JR,” says John. “I still say *different*, not *wrong*.”

When John joined Heather’s quest for answers, they were referred to local specialists—Dr. Deborah Simpkin, a child psychiatrist, and Dr. Karen Hagerott, a child neuropsychologist. In addition to undergoing an MRI and blood work to rule out various genetic and metabolic conditions, JR took a battery of IQ and psychological tests. His delayed speech was the factor that placed him just past the threshold of Asperger’s Syndrome, which, like autism, is a milder type of a pervasive development disorder (or PPD).

As a matter of fact, some of the “differences” that Heather and John describe in JR versus other children are so subtle that their closest friends were surprised by the diagnosis. The most obvious signs stem from language comprehension and socialization.

Grasping the nuances of language, for instance, does not come naturally. “If you tell him it’s raining cats and dogs,” says Heather, “JR might look outside to see.” His literal interpretations and black-or-white assessments make it hard for him to catch the point of jokes and accept that certain matters fall within grey areas. In contrast, he has an extraordinary memory that allows JR to recall information that he learned long ago. He also learns certain facts—like definitions of brand new vocabulary lists—speedily. Putting those same words to work in sentences, however, can require a long, concerted effort. Interestingly, too, he exhibits an exceptionally high aptitude for math and computer applications, but he cannot readily articulate how he derived his solutions.

While no cure exists for autism and, as John says, “no one hands you a brochure that outlines how to deal with the issues,” JR’s doctors have ordered child-specific therapies designed to foster his success in academics and social settings. In addition to medications that help with anxiety and brain development, their prescriptions include instructional programs that can best prepare him for a happy, productive life.

“The more you do for your child before the age of twelve, the better,” John says. Applied Behavioral Analysis (ABA), for instance, teaches children a variety of coping skills and appropriate responses. For several hours per week, JR attends an afterschool ABA program at Brilliant Minds, a locally operated resource that the Bowens praise for helping their son in many areas, like learning to make eye contact, choosing reasonable portions of food, understanding idioms, and reaching out to hug a loved one.

Throughout it all, whether laboring additional hours over his homework or dutifully attending Brilliant Minds, “JR takes whatever he has to do in stride,” says John. “We never wanted JR to use autism as a crutch, and he hasn’t.”

While proud of their son’s tenacity, the Bowens are equally grateful to live in a community with so much to offer, including the staff and teachers of Destin Elementary. “They have gone out of their way to make sure that JR receives everything he needs,” says Heather. In addition to Florida’s state-mandated Individual Education Plan (or IEP), requiring schools to provide accommodations like speech pathology and reading therapy to JR and students

like him, the Bowens say that he has benefited from devoted teachers and a principal who continually follow through to make sure their efforts are working.

Although JR has flourished in the public school system, the Bowens emphasize that the additional therapies not covered by State funding or private insurance are necessary. Because of Heather's persistence, the Bowen's private insurance company made a groundbreaking move recently by paying a portion of JR's Brilliant Minds tuition. Still, their remaining out-of-pocket costs tally hundreds of dollars per week. Such fees would be unaffordable for most families, especially those who have more than one autistic child.

"There is a definite need for fundraising," says John, who, with family and friends, have worked to raise money for the Emerald Coast Autism Society, a nonprofit organization that strives to provide assistance for those who cannot afford to pay for services. "A great deal of money has been invested to make the public aware of autism," adds John, "We must now make sure we care for each child."

In that endeavor, he encourages parents to investigate their concerns and then embrace their children for who they are. "Don't be ashamed or sad," he says. "I used to think I needed to fix JR, but I see now that he is not broken. He is a blessing. While I've been teaching him, he has taught me to see that there are many different ways to look at life."

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