

My Child Has Autism

by Janet Shouse, Parent

Our son Evan was 27 months old when he was diagnosed with autism. In 1998, 27 months old was considered very early for a child to receive a diagnosis of autism. So, unlike many families we know, our son was eligible for early intervention services. As awareness of autism has grown in recent years, more children are receiving a diagnosis of autism in time to receive early intervention services, which can make a vital difference in their lives.

Evan is a twin, and he and Brendan met the typical milestones of standing, walking, and talking within days of each other. Both boys were saying things like “mama” and “bye-bye” by their first birthday. But several months later we noticed Evan wasn’t saying new words like his brother was, and in fact, he wasn’t saying much of anything. Also, he often acted as though he couldn’t hear and never responded to his name. Given his history of ear infections, we were concerned about his hearing. He also preferred to be alone and seemed to lack a sense of danger that his brother possessed.

I talked with our pediatrician about my concerns. He preferred to wait until the boys’ two-year checkup to see where they rated on a developmental checklist. When Evan’s score was just half of Brendan’s score, Evan was referred to Tennessee’s Early Intervention System (TEIS). Our TEIS coordinator set up hearing and speech evaluations immediately.

Evan’s hearing was normal, but his language was the equivalent of an 8-month-old’s. The speech pathologist then referred us to a developmental psychologist. After we received the speech evaluation results, I told my husband, John, that I thought Evan was autistic. We did some Internet research at the Web site of the Autism Society of America and concluded that Evan’s behavior did indeed match those symptoms. Several weeks later, after the psychologist had evaluated Evan, we received the official diagnosis: Evan had autism. Even though it was what we had expected, it was still very difficult to hear.

I now realize that we were very fortunate to receive Evan’s diagnosis as rapidly as we did. It took just two months from the time our pediatrician referred Evan to TEIS until he received his diagnosis. Many families struggle for years and visit multiple doctors before their children receive an accurate diagnosis.

The psychologist then outlined the most important interventions for Evan. She listed, in order of importance, speech therapy, both group and individual, a developmental preschool class and occupational therapy.

Within three weeks Evan was in group speech therapy twice a week, individual therapy twice a week, in a developmental preschool three days a week and occupational therapy once a week.

Initially I was extremely pleased by what I saw at Evan’s preschool and depressed by his group speech therapy, because I saw stark differences in the two settings.

The preschool was a happy, colorful place that mixed typical children with children who had special needs, but Evan was extremely distracted by all the things in the room and seldom interacted with the other kids. A basic premise of this school was to let the child direct his own activities as much as possible. For Evan that meant roaming the perimeter of the classroom for most of the day and “swimming” in the sand when they went outside.

Meanwhile, the group speech sessions were held in a stark, bare room with a tile floor and a table and chairs. And the children were *made* to participate, using hand-over-hand prompts and other physical assistance when necessary. Although some of the kids would tantrum or “melt down” when demands were placed on them, I became convinced that Evan was learning much more in that setting than in his preschool.

Unfortunately, by the time I realized what Evan needed in a preschool he was nearly 3, and it was time to transition to the school system. In searching for other options, I looked into a relatively new — at that time — method of teaching children with autism called Applied Behavioral Analysis, but the one person I knew in our area providing such a service had a waiting list of a year.

Although I'm extremely grateful for the services we received through TEIS, I regret the amount of time I had to spend driving Evan to all his therapy and having to drag Brendan along. I'm glad that early intervention services now are much more likely to be delivered in the home and to incorporate the family. Our only in-home assistance came through the Tennessee Infant Parent Service, which brought a teacher into our home for an hour a week to help us learn how to teach Evan.

I am thankful that we had 10 months in the early intervention system before we had to transition to the local school system. Those 10 months allowed us to have independent evaluations and a significant amount of therapy, without having to worry about how to pay for those services. Those 10 months also gave us time to learn about autism and how it affects our son. And those 10 months allowed us the opportunity to learn about our son's rights under the Individuals with Disabilities Education Act (IDEA), so that we were able to go into our first IEP meeting well-prepared. Evan is now 7 and has finished first grade, where he spent most of the day with his typical peers in a general education classroom. He has an assistant with him throughout the day, both to help keep him safe and to keep him on task. The curriculum is modified for him, and some accommodations, such as the Picture Exchange Communication System, are used. Although Evan still has very low expressive language skills, his receptive language skills are quite good. And despite his lack of communication and social skills, he has lots of friends at school, kids who are willing to help him, talk with him, and play with him. For us, that has been such a blessing.

There are some things I'd like to share about our experience that might benefit other children with autism:

Listen to the parents: Many times they will know something is different about their child long before the pediatrician or other professionals recognize or admit it.

Learn the early signs of autism: Children who don't point or babble by 12 months, who don't use any single words by 16 months or who lose any language or social skills at any age should be evaluated immediately, according to the American Academy of Neurology.

Understand that children with autism may require different teaching strategies from those used for typical children or even for children with other types of disabilities, but they still need time with typical peers.

Obtain additional information: Visit the Autism Society of America's Web site at www.autism-society.org/site/PageServer and the Autism Research Institute's site at www.autism.com/ari/contents.html.

Start with useful books including: "A Parent's Guide to Autism," by Charles A. Hart; "Children with Autism: A Parent's Guide," by Michael D. Powers; "Autism Treatment Guide," by Elizabeth King Gerlach; and "Children with Starving Brains: A Medical Treatment Guide for Autism Spectrum Disorder," by Jaquelyn McCandless.

The Shouse family includes John, an engineer and the president of the Autism Society of Middle Tennessee; Janet, a newspaper copy editor and county contact for the Autism Society of Middle Tennessee for Williamson County; daughter Emma, who will be starting high school this fall and wants to be a speech pathologist; son Brendan, who is 7 and loves to ride his bicycle; and Evan, who loves Disney movies and swimming.