

When Your Child Has Autism

by Carrie Smoot

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More than 1.5 million people in the United States have autism, an incurable lifelong brain disorder affecting communication, behavior, social, cognitive, and motor skills. The cause is still a mystery, but some people believe it's genetic or related to diet and childhood vaccinations. Autism is the most common pervasive developmental disorder (PDD), often linked with developmental delay and autism spectrum disorder.

PDD may carry the "not otherwise specified" (NOS) label. The National Alliance for Autism Research (NAAR), in Princeton, N.J. says autism spectrum disorders occur in an estimated one out of 250 births, making autism the second most common developmental disability. Some studies place autism's prevalence even higher.

"Currently, no medical or biological test diagnoses autism," says Dr. Eric London, NAAR co-founder, psychiatrist, and father of a son who has autism. NAAR has committed more than \$10 million to directly fund 119 autism research projects and fellowships worldwide. Most projects are U.S.-based. "The research is moving in all directions," London says. "We have a clue that it is genetically based, and some studies center on the immune system and environmental factors. We still don't have very good treatments, and some are dangerous. As a parent, you really have to do a lot of homework."

Johns Hopkins University child psychiatrist Dr. Leo Kanner discovered autism in 1943 and noted behaviors associated with it—fascination with certain objects, unusual body movements like spinning or flapping arms, repetitive language and unresponsiveness. No two diagnosed children are alike, and autism tends to appear four times more often in boys than in girls. Some children are nonverbal, completely aloof and very repetitive, while others are mildly socially awkward, have unusual conversational styles and pursue unique interests. Those with savant skills may be unable to communicate effectively but are gifted in certain areas, like music or mathematics. "High-functioning autism" means the child has normal cognitive and learning abilities, but fits other characteristics related to autism, and may have had difficulty acquiring language.

Children with Asperger's syndrome are similar to those with high-functioning autism, but have fewer symptoms and no difficulty developing language.

Dealing with the Unexpected

One Virginia family was unprepared for the diagnosis. Signe Kavanagh is the mother of 4-year-old Liam, who was diagnosed with autism. "I felt like we lost everything. It's like having a changeling. I felt guilty because I stayed home with him. Development was normal—he even began talking early. Right after his measles, mumps and rubella (MMR) shot, he regressed. We went through some very trying times at first. He screamed for hours at night, tantrummed many times a day, and sometimes would just laugh a lot at some mysterious cosmic joke. He became unresponsive, nonverbal and stopped making eye contact." Because younger sister Josie was just born, his parents thought Liam was jealous. Medical test results were normal. Both parents asked whether Liam had autism, but the pediatrician said to wait. Eventually, there was no doubt. "Caring for a child with autism is a 24-hour job that taxes you and your family in every way," Kavanagh says.

Children's Hospital in Richmond offers specialized medical and therapeutic services to children and adolescents with temporary medical conditions and lifetime disabilities, including autism. Pediatricians and specialists take a team approach when discussing treatment with parents. Depending on needs, the child may see a developmental pediatrician, an occupational therapist, speech therapist, orthopedist, psychologist, psychiatrist and others.

"The earlier the intervention, the better the outcome. The ideal age for diagnosis is between 18 and 24 months," says Pasquale "Pat" Accardo, M.D., developmental pediatrician at Richmond's Children's Hospital. "There's no reason that some [children] with autism couldn't eventually live independently, hold down a job and lead a full life, with appropriate needs addressed. It depends on the disorder's severity and accompanying deficits like mental retardation and speech and language disabilities," he says.

Accardo says it's difficult for some pediatricians to spot autism during well-child visits because most behaviors are those of typically developing children—just more intense and prolonged. "Much is based on observation. If parents suspect problems, they should ask their pediatrician for a referral to a developmental pediatrician, child neurologist or child psychiatrist with some special interest in autistic disorders."

Dr. John Suozzi is a Children's Hospital clinical psychologist. He focuses on improving child skills in several areas, including communication, play, socialization and interpersonal relatedness, and addresses challenging behaviors commonly seen in autism. Suozzi advises parents about treatment needs and options. "Autism has tripled across Virginia," he says. "Because news of a diagnosis can be so overwhelming, it is best to involve parents at the outset. Early intervention before age 5, use of applied behavior analysis, and a team approach are the key elements to good outcomes."

Suozzi is careful to define and to describe autism thoroughly for parents, explaining deficits clearly and concretely. "Parents should never lose hope. At the same time, they have to be realistic." Suozzi says the only research-supported intervention for treating children with autism is applied behavior analysis, or ABA. From ABA come several teaching techniques and strategies to treat the challenging behaviors seen in autism.

Suozzi says children with autism have great difficulty with social cues such as responding to others, imitating people's actions, and understanding the "give and take" of socialization. These children have poor play skills—especially pretend play. Suozzi uses positive reinforcement strategies that help children see him as a source of enjoyable things. He says having predictable routines helps children to know what to expect.

Intensive behavioral treatments covering school and home environments are needed for these children. "Parents can help to continue what's covered in a session. They need to develop routines and to maintain order at home while still being fair to all family members. It's a real balancing act."

Parental Support

One of the best forms of support in the southwestern and southern parts of the Commonwealth is the connection with other parents of children with autism. Cherie Arnn, a behavioral therapist who works with children with autism and recently started the Piedmont Autism Action Group, says that parents can be very helpful in assisting other parents. "Parents really support one another," she says. "especially with the IEP meetings." Arnn states that if a parent is looking for additional services for their child, often another parent will help out by going along to the IEP meeting as support.

There are a number of active support groups in the area that offer friendship and fun, as well as advice and assistance (See **Community Resources Tab** on the Celebrating Special website - www.celebratingspecialchildren.org). These groups meet on a regular basis and through this unity, can schedule conferences and other events, as well as try to gain access to better services for everyone's children. ■

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Occupational therapist Debbie Geauthreaux explains balance and coordination while Nick Zempolich tries to balance on the balance beam during Fairfax County's Union Mill Elementary's Autism Awareness Week.

