

# Support Groups Aid Autistic Children's Parents

By Aline Renauld Prince

*"Mom, you should see what I saw on television," said enthusiastic, blond Nicky as he bounded into the room. "The sphinx moved and was singing."*

**Nicky** handsome 8-year-old son of Elizabeth Gerlach. He was diagnosed around the age of 3 as having autism. His parents suspected there was something not quite right with Nicky, but getting a correct diagnosis was difficult, as it often is with this severe developmental disability.

Though it doesn't go away, it can be treated. Nicky learned to make eye contact and to converse by the time he was 5 years old. Today he expresses himself very clearly, with only slightly aberrant speech.

Elizabeth said, "Of course I was devastated when we got Nicky's diagnosis—went through the usual denial, anger, grief, and so forth." Gerlach said, "Coming to terms with it is a never ending, layered process. I wanted to find out about autism and available treatments, and was dismayed I had to do this on my own."

That is why she wrote "Autism Treatment Guide" (Four Leaf Press). "Early intervention is crucial," she says. Her 130-page book is packed with names, addresses, and phone numbers of therapists, national organizations, and resources, plus suggested reading lists. It is available from The Book Bin. She does not recommend any special treatment, as each autistic child needs a program tailored to her needs.

This early onset illness happens four times more often to boys than to girls. It strikes 15 in every 10,000 children, and is considered a neuro-biological disorder located in the brain. It affects children throughout the world regardless of race, color, or social background.

Diagnosis of autism is best undertaken by an interdisciplinary team which would include specialists in a variety of areas, such as psychology, pediatrics (with autism treatment updated), educational diagnostics, speech/language pathology, audiology, and social psychiatry.

Because autism is behaviorally defined, the patient's behavior would be evaluated at various times and in different environments.

Though often not officially diagnosed until your child shows an inability to learn customary speech, earlier signs are usually evident. He may not have been an outgoing or cuddly baby, may have engaged in repetitious, unimaginative play, such as endlessly lining up toy trucks. Early on, he may have exhibited excessive rocking, head banging, a blank stare, self-stimulating body movements, or tantrums.

Not all children with autism exhibit the same symptoms. The syndrome can affect learning, speech, reason, the five senses, or the inability to generalize. Symptoms may include an impaired ability to perceive sensory input accurately; the child may feel that a caress is a punch, or may not feel touch at all. Autistic boys or girls may be overwhelmed by distorted visual sensations. They

may remain mute, or not learn to converse, though endlessly repeat television commercials. Eye contact may be impossible without therapy.

The child may have bionic hearing or may find it difficult to modulate sounds; for instance, she may scream when the lawn mower is operating. The child may have difficulty learning to read, while on the other hand, her area of savant mastery may be to read well at an early age.

According to Rosemary White, a licensed physical therapist, occupational therapist, and teacher for Sensory Integration International, “Though some children with autism are also mentally retarded, you want to think about other autistic children as not being mentally retarded, rather that some areas of their learning are impacted while some are enhanced. Autistic children are developmentally delayed because learning is not only academic, but also social. I see some whom I know are very bright. But they are in Special Ed, because they cannot learn without a special environment.”

Comparing therapy today to the early ‘40s makes 50 years ago seem like the dark ages when this syndrome was not understood and treatment consisted of being locked away. The affected child was thought to be retarded, plus have severe emotional problems. The cause of autism was thought to be bad parenting.

Though there are no miracle cures, much progress has been made. Current treatment helps the autistic patient function more normally in the world, and smoothes the path of daily life for the child and parents. The parents who follow and implement the child’s therapy at home become a valuable resource for treating the autistic child.

Parents of autistic children form support groups. Says Ms. Gerlach, “It’s not only a great source of moral support—it builds solidarity. When you have a disabled child, you have to become an advocate. It’s a double whammy when your child’s welfare is up to you, and you are trying to sort out what has happened. These groups—the friends I have made there—help me deal with the ongoing problems of doing what is best for my child, help me learn strategies to negotiate with the school district.”

Some of the available therapy isn’t embraced by the medical community. Parents agree it is they who must evaluate and decide what is best for their child. And it’s up to them to follow the therapy at home. “You have to trust your own instincts,” says Gerlach. “What helped Nicky a lot was to clean up his diet, often the most difficult thing to change. Some of the therapies like auditory integration treatment really helped Nicky. It retrained my son’s perception to sound, and that helped him focus his concentration, his ability to open up to the world. But that doesn’t mean it would work for another autistic child.”

Gerlach reported that the best thing parents can do for their child who is autistic, for their family, and for themselves, is to accept and love the child exactly as he is. “It is critical, and so very hard,” she said. “It helps to let go of all your anger, your frustration. Stop thinking of your child as a label. Though it’s not easy, it’s well worth the effort.”

Nicky bounded into the room again. His mother said, “I’m almost through. You go ahead and start working on the computer without me.”

“Can I go ahead?”

“Yes,” his mother affirmed.

Clearly, indeed, Nicky would go ahead with love supporting him.

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