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Local autism advocate set to retire

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When Ruth and William Sullivan were living in upstate New York, a man knocked on the door and asked if they knew there was a kid on their roof.

"It was our 4-year-old son, Joseph," Ruth Sullivan said. "He was amazingly agile. Some autistic children are."

Sullivan can recall the day when Joseph, now 47, was first diagnosed with the disorder.

"We were living in Lake Charles, La., when Joseph was born in 1960," she said. "We'd never seen anything like what we'd seen from our young son. There was such early progress.

"He was a little genius at 18 months old, then it just turned off like a water faucet," she recalled.

She made an appointment with a psychiatrist to help diagnose their son.

"I had heard the word autism in graduate school but I had no idea what it meant," she said. "The psychiatrist said Joseph would be a little odd. Little did I know what he meant."

From that point on, Sullivan has dedicated her life to working for autistic children and adults. She has spent four decades working with people with the disorder and their families, helping them find the services and support they need.

Now the 83-year-old is about ready to finish the professional end of her cause. She's retiring at the end of the month from the Autism Services Center that she founded in 1979.

The facility started at her dining room table, where Sullivan started reaching out to other parents of autistic children.

As long as she has Joseph, though, she'll never put her autism effort behind her.

The Sullivans didn't know what was wrong with Joseph at first, but they caught on quickly. They learned all the children exhibited the same behavior patterns -- lots of physical posturing, not sleeping, hypo or hyper-activity, poor or no speech and extreme aloneness.

The name autism, comes from auto, meaning self-contained, self-centered. It was as though the children with the disorder were alone in the universe.

"Joseph was a classic case. We knew what was going on," she continued, "but it's so sad when parents don't know."

When Joseph was diagnosed, the Sullivans met with parents and other health-care professionals. Ruth went to a group therapy session that was suggested by another psychiatrist. That was in 1964 in Albany, N.Y., and it was the beginning of her life's work.

The family moved to Huntington, where William took a position on the faculty at Marshall University. One of the reasons the family located in Huntington was Cabell County's program for autistic students in the school system. The Sullivans were impressed that the county was one of the first in the country with such a program.

Ruth founded the Autism Services Center in 1979 to help parents and people with autism from diagnosis to death. She has a bachelor's and master's degree in public health nursing and administration from Columbia University and a Ph.D. from Ohio University.

She immediately started organizing parents, getting what was needed to help autistic children and adults and lobbying for money and educational opportunities. Parts of her lobbying efforts were directed to get mandated education and improved services for autistic children and adults.

As autistic children get older, they need more help with social skills training," Sullivan said. "It does not come to them intuitively. Typically, most autistic children and adults seem not to care what you think. Studies have shown that as their social skills increase, the savant skills are not as close to the surface as they once were."

The center currently serves 280 families in four counties with a staff of 400. "We put services in the homes of families, get the children and adults into group homes and help them get into school," she said.

Among her accomplishments was the development of an autism training center at Marshall University, the first such center in the country. It has a special focus on children with autism in the classroom and training of teachers.

"Joseph started school when he was 7 years old before the federal-state mandate," she said, "only because he had a mouthy mother."

Today, there's a sharp increase in the number of children that are diagnosed with autism.

In 1968, a study estimated one in 2,500 children was diagnosed with autism.

"Now, I've seen recent studies that say it's one in 156 children and another recently completed said it was one in 77 children diagnosed each year with autism," she said.

"These days you don't talk to many families without knowing someone who has autism or a family affected by the disorder."

Sullivan believes that the number of vaccines a child has before he or she is two years old may have a direct correlation to autism.

"To me, it points in that direction," she said. "By the time a child is two years old, they have had 33 shots. If there's mercury in those vaccines it collects in the brain. These children sometimes get five to six vaccinations at a time.

"In that much dosage, it's very hard for an immune system that might already be compromised to get the mercury out of the body," she continued. "There's a theory that there are certain children who are vulnerable to immune system diseases and cannot handle the mercury. Those children could be more vulnerable to autism."

Even with all that's being done today in research on autism, Sullivan doesn't see a cure in the near future.

"Fifteen years ago there was not much research being done at all," she said.

Now that has improved with more research being done at the National Institutes of Health and other facilities, she said. Marshall itself got a Centers for Disease Control and Prevention grant to study autism.

When she retires Oct. 31, Sullivan says being able to visit with her seven children and 11 grandchildren will be on her list of things to do. While Joseph lives in Huntington, her other children are scattered around the country.

"I'll be cleaning out closets too," she said. "I want to continue doing some writing and most of my research is stuffed into some of those closets at home.

"I'll still be interested in what's going on here at the agency as I have accepted the invitation to continue serving on the board of directors, but I'm not going to be a hovering retiree," Sullivan said. "I'm a mother who will watch, but the agency will go on, well guided by people who know what needs to be done. Very good people are right behind me."

Joseph now lives in a very good placement, in a good house with very good staff, his mother said.

"It's expensive and very hard to do, but you do anything for the good of your children.

He was one of two major autism models used as the subject of the movie, "Rain Man," and his mother served as a consultant for the film.

Dustin Hoffman, who played the part of the autistic adult "Raymond," visited with the Sullivans before the film was made. When the movie premiered at the Keith-Albee Theatre in Huntington, he, along with Barry Levinson, the director, and Mark Johnson, the producer of the film, attended the event.

As an autistic-savant, Joseph shows a propensity for special skills.

"He's good with numbers," his mother said. "He can remember license plate numbers, maybe not your name, but he'll remember dates and times.

"Joseph can multiply two four-digit numbers in 12-15 second or less," she said. "And he has perfect pitch."

Sullivan said it's a mystery why certain autistic children display certain skills like excellence with numbers or math, recognizing things, memory skills and musical abilities far above their proficiencies.

"Children with autism have a spark in their eyes," she said. "There's something very alert going on in there. They may not talk but they are always taking things in."

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