Life on the spectrum

Families learn to maneuver the ups and downs of autism

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LAS CRUCES - As Angelo, 9, and his younger brother Emilio, 6, play together outside of the Autism Resource Library at Centennial High School on a Friday afternoon in early March, they appear to be typical well-behaved young boys, laughing and making up games with whatever toys they can find.

But the two weren’t always this manageable, said the boys’ mother Marisa Cano, 35, who helps run the Autism Resource Library, a public library formed by Las Cruces Public Schools and the Hearts for Autism Fund, a local nonprofit, to provide books, toys and resources for families who have children on the autism spectrum.

When Angelo was 2 years and 9 months old, he was diagnosed with autism spectrum disorder, a developmental disability that can cause significant social, communication and behavioral challenges. Cano said she later recognized the signs and symptoms of autism in her younger son Emilio, who was diagnosed at 2 years and 11 months old.

“Once you have one child with autism, you’re at a higher risk to have additional children with autism,” said Cano, also the executive coordinator for the Hearts for Autism Fund. “I was watching (Emilio) and I knew (he had autism.) I would see him stacking things and sorting by shape and color when he was 1 1⁄2 years old.”

Cano said when she and her husband first received the news that Angelo had autism, it was devastating and they were nervous about taking him out in public because of some of his behavior.

“I think what’s really common with parents who have kids with autism is that they isolate themselves, and we did the same thing — especially with Angelo when we got the first diagnosis,” Cano said. “I think it was almost two years before we resurfaced out in the community, talking about it and going out and being part of groups.”

While there is often nothing about how people with autism spectrum disorder look that sets them apart from others, people with ASD may communicate, interact, behave, and learn in different ways, according to the Centers for Disease Control and Prevention.

“Autism is an invisible disability, so you can’t tell they’re having sensory or behavior issues,” Cano said. “It just looks like you’re not a good parent or you can’t control your child, and then people get judgmental and it can be kind of hard and you don’t want to hear those comments.”

Since their initial diagnoses, early intervention, therapy and a strong support system have helped Angelo and Emilio reach a level in which they are able to interact with others and listen to instruction.

Angelo goes to Sonoma Elementary School, where he is in a specialized site for kids with high functioning autism and Emilio goes to J. Paul Taylor Academy, where he is in an inclusion classroom and gets support from a behavioral therapist, Cano said.

Understanding autism

April is National Autism Awareness Month and in the U.S., about 1 in 68 children have ASD , according to CDC.

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The condition includes a wide range of symptoms, skills, and levels of impairment or disability, with some children only mildly impaired by their symptoms, while others are severely disabled, according to the National Institute of Mental Health.

“When (people) think of autism, they automatically think very low functioning, and really autism is not just that; it’s a wide variety,” said Myrna Trujillo, clinical director at Mariposa Autism Service Center in Las Cruces. “If you’ve met one child with autism, you have only met one child with autism, because everyone is so different.”

Signs a child might have ASD include not responding to their name by 12 months, not pointing at objects to show interest by 14 months and not playing “pretend” games by 18 months. Other red flags include avoiding eye contact, trouble understanding other people’s feelings and delayed speech and language skills, according to the CDC.

“Nearly 25 percent of kids who are diagnosed with autism are nonverbal and 50 percent do not have functional speech and nearly 50 percent of the kids who are diagnosed with autism have cognitive delays and developmental issues,” said Sathiya Ramdoss, an assistant professor in the Department of Special Education and Communication Disorders at New Mexico State University.

In order to make a valid diagnosis for autism, the child must be at least 2, Ramdoss said.

Theories and research

Brain scans show differences in the shape and structure of the brain in children with autism, but the exact cause is unknown. Theories as to what may play a role include links among heredity, genetics and medical problems, according to the Autism Society.

“From the genetic point of view, if either one of the parents has genes associated with (autism), there are possibilities for inheriting that gene,” Ramdoss said.

However, no one gene has been identified as causing autism and researchers continue to look for irregular segments of genetic code that children with autism may have inherited, according to the Autism Society.

“Even in identical twins, the chances for having autism in both kids is 60 to 90 percent — it’s not even 100 percent,” Ramdoss said. “So we have possibilities for some other factors also playing in this.”

Recent studies have also looked at the link between autism and spontaneous, or de novo, gene mutations.

“(De novo gene mutation) is not found in either of the parents, but it’s happening in early prenatal development,” Ramdoss said.

Treatment and resources

While there is no cure for autism, early intervention, therapy and education can help lesson disruptive behaviors, teach self-help skills for greater independence and give people with autism the skills to function in a social world, according to the Autism Society.

“People have a hard time understanding, just in general, that (autism) is a lifelong event that these kids are going to have to deal with, and we have to help them as parents do, but even more so, on that journey to adulthood,” Steven Cano, 39, Angelo and Emilio’s father, said.

In Las Cruces, the support and resources available for families and individuals with autism is growing, he said.
Mariposa Autism Service Center, 120 Wyatt Drive, is one resource that focuses on Applied Behavior Analysis, or ABA.

“ABA is one of the interventions used for children with autism and is recognized internationally, so it’s a set of techniques and principles that explain how learning takes place and how we interact with the environment,” Trujillo said. “Based on these techniques and principles, it brings out meaningful and positive change and behavior.”

Trujillo said when choosing an intervention method for your child, it’s important to make sure it is research based.

“We want to make sure the child is receiving services that are proven to work,” she said. “There’s some unsafe interventions on the Internet.”

Finding support is also important. LCPS provides an Autism Support Group for families of students with ASD in which parents can get training or present problems they may be facing, said Morgan Harding, autism specialist for the LCPS Special Education Department.

“We want to help (parents) bridge the gap between home and school and help their child be successful in the home and in the community,” Harding said. “Parents play a really important role in the child’s life, so we know if we help the parent then that helps the long term progress of the child.”

Along with support groups, LCPS hosts a Special Olympics Project UNIFY event each year in the spring called the Autism Awareness Team Building Competition, in which general education elementary school students work with their autistic peers to practice team building skills, such as a three-legged race, team poles, summer skis and tug-of-war. The event teaches awareness and acceptance of people with disabilities.

The Hearts for Autism Fund also plays an active role in the autism community by providing monetary stipends, a summer camp for children and young adults with autism, free community training workshops and promoting public awareness through fundraising events.

Building a bright future

While many people still have misconceptions about autism, Harding said she thinks people are becoming more accepting of people with disabilities.

“Watching the peers in the schools, you can see their understanding of people with disabilities and I think that’s mostly due to exposure — just being around a child with autism and saying, ‘Oh well, they act a little differently,’ but they still accept them for who they are,” Harding said. “They’re different, not less.”

The Canos said their hope for their children is that they will have a good quality of life, be able to find employment and live independently, without having to rely on government services.

“I think that’s what most parents want is a good quality of life for their kids and that’s where these kind of things (early intervention and building a strong support system) come into play,” Marisa Cano said.

Parents of children with autism often have to deal with fear of the unknown and uncertainty about what the functionality of their children will be once they reach a certain age, she said.

“Every year, every day (Angelo and Emilio) are blowing apart what I thought they were going to be able to do,” Marisa Cano said. “We’re just going to keep pushing for as much as we can, advocating for as much as we can, so
that there’s no perceived box of what they’re going to fit into, and we’ll go with that. As we get closer and closer (to adulthood), I guess we’ll find out where we’re at.”

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Marisa and Steven Cano watch their 9-year-old son, Angelo, play with a tablet app at Centennial High School’s Autism Resource Library.

While students at Central Elementary School practice for Project UNIFY, an Autism Awareness Team Building Competition, Eric Lin, 6, looks up at the camera wearing a shirt that reads, “Different Not Less.” ROBIN ZIELINSKI / SUN-NEWS