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Autistics face rough road in LV

Support, treatment are improving

By [Ed Koch](#)

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Krista Vance is grateful for doctors in Colorado, California, South Carolina and Massachusetts.

When Vance's son Jamie was diagnosed at age 2 with autism, the developmental disorder that affects communication and social interaction, she left Nevada, trekking across the country to find doctors who could help.

"The problem that we parents face is that the medical industry does not give us many options," said Vance, 42, who along with her 39-year-old husband, James, are local restaurateurs. "We had to do all of the research to find doctors to get our child diagnosed and treated.

"At that time we were not as successful as we are today. It was a great struggle for us financially.

"We spent thousands of dollars. No place was too far to travel. No treatment was too costly to consider."

And there were no apparent answers in Nevada, where there's a serious lack of doctors and treatment facilities for autistic patients.

"When parents of autistic children in other states tell their doctors they are thinking of moving to Las Vegas, those doctors often tell them 'don't' - that's how bad the problem is here," said Dr. Johanna Fricke, the only board certified development/behavioral pediatrician in Nevada.

To see Fricke, on staff at the University of Nevada School of Medicine in Las Vegas, it can take up to two years for someone to get an appointment for an autism screening.

In the last year, two major California-based autism centers have set up shop in Las Vegas - the Lili Claire Foundation and the Lovaas Center - making it somewhat easier for parents to get help for their children.

However, with the Nevada Legislature last year cutting \$4.5 million in funds earmarked for autistic care from the budget, experts say there is a long way to go to get adequate help for autistic children and their families in Southern Nevada.

A bigger issue is the shortage of doctors.

Many insurance companies and Medicaid don't cover the often expensive treatment for autism because it is too broad an ailment. And with an estimated 1.5 million Americans suffering from autism, it's not a big enough field to attract doctors.

Those doctors who do specialize often go to bigger centers where their work will be supported.

"Like anything else, it comes down to money," said Fricke, who left 22 years of private practice to join the medical school because she couldn't afford to continue on her own.

Slowly improving

Jan Crandy, a Las Vegas resident of 25 years and co-founder of the autism support group FEAT - Families for Effective Autism Treatment - said there are plenty of stories like the Vances' story in Southern Nevada.

"When my daughter was diagnosed in 1996, I had to go to California to get that diagnosis," she said. "Things are improving here, but slowly."

Earlier this month, Crandy appeared before the Legislative Committee on Persons With Disabilities to speak on behalf of one small state program that is helping 17 families of severely autistic children by paying for in-home behavioral intervention services.

If the Legislature approves \$4.5 million next year, the program will be expanded to help 140 families.

But, with nearly 1,900 Nevadans identified under the single label of autism, there are hundreds more who have autism and other disabilities who aren't helped.

"Other states are starting to write bills that mandate insurance and Medicaid coverage, and that is what Nevada needs to do to solve this problem," Crandy said. "Every child deserves appropriate services - not just those whose parents can afford it."

The nonprofit Lili Claire Foundation agrees. It does not ask patients seeking diagnoses whether they have insurance. The clinic is partnering with Fricke and the medical school to increase free diagnoses for autism.

"When we looked at Las Vegas, we saw that there was just two support groups for autism and no diagnostic help," said Jennifer Bradley, program director at the Lili Claire Foundation clinic at 522 E. Twain Ave. "Since June, we have grown from holding twice-monthly clinics to weekly clinics."

Lili Claire, which previously had established clinics at UCLA and Vanderbilt universities, intends to start offering autism behavioral therapy this spring.

The Lovaas Center from Southern California, which also focuses on autism behavioral education, set up shop in northwest Las Vegas late last year. It focuses on Aspergers, a type of autism.

School boom

Over the last five years the Clark County School District has seen a 200 percent increase in students who have been diagnosed as autistic, an increase fueled not only by the population boom but also by increased awareness of autism.

District officials say there are 1,400 known autistic students enrolled.

Las Vegas autism advocate d'Arcy Bostic said the district can't hire enough qualified special education teachers. She notes that her son has gone for three years in classrooms for autistic students without a full-time special education teacher.

"It all starts with the School District - if we do not have qualified special ed teachers, then children like my son will not learn to function to the best of their ability," Bostic said. "I feel frustrated and sad because the School District apparently does not understand the long-term ramifications of such situations."

The class is run by a full-time substitute teacher, and school officials say all teachers who work with autistic children are given special training.

Cynthia McCray, the district's director of low incidence disabilities, said each autistic child is evaluated by a team, which includes parents, administrators, teachers, psychologists and speech pathologists, that charts a student's academic course.

She agreed that it is getting difficult to find teachers and provide all of the services needed, given the explosive growth of the number of autistic students. The district's program for autistic children starts before they are school age.

Bostic's son took those classes and also received private speech and sensory integration training to help calm him down so that he could better absorb the information and instruction he received.

In her son's case, she said, the School District's preschool program for autism was superior to its school-age program, as her son had a special education teacher in the early program.

"Treatment and education for autism is a long process - a lifelong process," Bostic said. "Every step, including what is offered - or not offered - can affect children with autism."

Jamie's story

Because Jamie has come a long way since being diagnosed with autism, his mother considers him cured. Experts, however, say that while many autistic children make some improvement and become functionally independent, there is no cure.

Still, Jamie's doctor, Terry Grossman of Colorado, said Jamie's progress has been remarkable.

"When Jamie first came to see me, he had no verbal skills whatsoever," Grossman said. "He was very poorly behaved and hyperactive. I find it gratifying when children reach such a level of normal functioning. They become normal children."

Jamie seems like a normal 8-year-old. He loves video games, basketball, tennis, rollerblading, skiing and swimming. His taste in music ranges from Celine Dion to U2 to the "Shrek" soundtrack. In school, he enjoys reading, art and science.

He is an Honor Roll student. Jamie and his twin brother, Jack, who is not autistic, dream of both being pro tennis players.

But Jamie's success to date did not come without taking a heavy toll on his family, especially his mother.

"Being the mother of a child with any disability is immensely difficult," Vance writes on her Web page healingautism.com, which she established to help parents find autism doctors and treatment facilities. "It overwhelmed me."

She said the stress over the years made her ill, and "at times it was so bad I felt like part of me was dying."

Two years ago, Vance gave birth to another set of twins - daughters Sofia and Gabriella. Gabriella recently was diagnosed with cerebral palsy.

"I guess," Vance said, "she will be my next project."

Ed Koch can be reached at 259-4090 or at koch@lasvegassun.com.