The key to his future

Thanks to early intervention, autistic child's growth holds greater promise

By LISA PALMER, Standard Times correspondent

Three-year-old Sebastian Oliva of New Bedford sits cross-legged on the top bunk. He is watching Saturday morning cartoons in the bedroom he shares with his older brother. For a few seconds, the curly-haired preschooler glances away from the TV, eyeing a visitor standing in his bedroom doorway.

"That's good," Sebastian's mother, Leslie Pereyra, tells the visitor to her Division Street apartment. "He looked at you. We want him to look at people."

Ms. Pereyra and Sebastian's father, Christian Oliva, also want their son to talk. Smile. Eat. Cry. Play.

At 22 months old, Sebastian was diagnosed with Pervasive Developmental Disorder (PDD), an umbrella term that includes Sebastian's specific disorder: autism.

Autism has a wide array of symptoms that vary in degree, but is largely characterized by impaired communication and interactive skills. Some autistic individuals are extremely sensitive to sound and touch; others adopt repetitive behaviors. Developmental delays are common.

A complex neurological disorder that typically appears in the first three years of life, autism is four times more prevalent in boys than girls and knows no racial, ethnic or social boundaries, according to the Autism Society of America.

While there is no cure for autism, recent research indicates that early diagnosis, before the age of 3, combined with intensive treatment will substantially improve an autistic child's future developmental progress and independence.

Sebastian began learning communication basics like making eye contact and other life skills in rigorous early-intervention programs he received at home over the last year and, since January, in the Applied Behavior Analysis program at New Bedford's Carney Academy.

Soon after Sebastian's first birthday, Ms. Pereyra began noticing that her son's behavior was not like that of his older brother and sister, both lively, outgoing and playful children.

Sebastian was quiet. Too quiet. He lolled in his crib long after waking, staring at objects in his room.

"He was not a needy child," Ms. Pereyra says. "He would wake up in the morning and I wouldn't even know he was awake. He never cried."

At 15 months, he was not yet walking. He wasn't trying to form words. He didn't eat solid food.

In many ways, caring for her son seemed too easy, Ms. Pereyra says. Then it hit her. Something was wrong.

"He would have been a dream child if it were normal," Ms. Pereyra says. "But it wasn't right. A baby should need his mom."

In February 2003, Ms. Pereyra and Mr. Oliva learned the root of their child's apparent calm. Doctors at St. Luke's Hospital's Child Development Center made a professional diagnosis, and six months later doctors at Children's Hospital in Boston confirmed the boy's autism.

Ms. Pereyra, who is originally from the Dominican Republic, says discovering Sebastian had autism was overwhelming.

"They throw you a bomb and you're like, oh my God. It's like death," she says.

Much of Ms. Pereyra's family, including her parents, sister and brother, moved to New Bedford following Sebastian's diagnosis.

While Leslie and Christian had suspected a developmental delay, and even autism, it was hard to accept the diagnosis when it finally came.

"All along, I was telling myself that Sebastian's OK, until you get the official news," says Mr. Oliva. "Then you start dealing with it. You have to be strong, you know, for your family. But you want to sit down and cry."

"You think all autistic kids show no emotion or don't want to be touched," says Ms. Pereyra. "But Sebastian is very affectionate. Very lovely. He likes to joke. He likes tickling. His being affectionate wasn't consistent with what I thought autism was."

The incidence of autism in the United States appears to be growing, perhaps dramatically. Accurate figures are the subject of intense study nationally, as well as in the state of Massachusetts.

The Centers for Disease Control and Prevention reported in 2001 that autism and other PDDs (which include Asperger's and Rett's syndromes) occur in approximately two to six in 1,000 individuals. The CDC is working to get a more accurate fix on statistics.

The occurrence of autism in children is higher than that of Down syndrome, cancers and spina bifida, says the CDC. As many as 1.5 million Americans are thought to have autism today.

According to Roseanne Pawelec, spokesperson for the Massachusetts Department of Public Health (DPH), the state "is trying to get a handle on the number of people in Massachusetts affected by autism. Right now, there's an absence of statistics."

While the DPH is studying this issue, there are dramatic figures relating to young children. According to Tracy Osbahr, coordinator of specialty services at DPH, the prevalence of autism and other PDDs in Massachusetts children between the ages of 18 and 36 months is approximately one in 175, a huge jump from 10 years ago when the incidence of the disorder was reportedly one in 5,000 in the state.

"The Department of Public Health is concerned about the increase in numbers," Ms. Osbahr says. "The generic early intervention services (such as speech and occupational therapy) were not set up to provide the kind of specialized programming kids with autism need."

Although no one is certain, Ms. Osbahr says more accurate diagnostic tools for younger children and increased awareness is one explanation for the jump in the number of Massachusetts children diagnosed with autism in the last decade.

Nationwide, another theory, though not proven, suggests a link between the onset of autism and infant immunizations, specifically the MMR vaccination.

Since 1998, the DPH has contracted with about 10 autism specialty services statewide to provide in-home applied behavior analysis (ABA) for children, which researchers and clinicians consider the best treatment for autism.

ABA is one-on-one therapy, provided by a trained professional that improves overall behavior through a reward strategy and also strengthens communication skills. Beacon, the May Institute and Children Making Strides are among providers that serve the SouthCoast communities.

Autism's annual cost to the U.S. economy runs in the billions of dollars; 90 percent of those costs are in adult services. According to the Autism Society of America, the cost of lifelong care can be reduced by two-thirds with early diagnosis and intervention.

Early therapy can help neurological pathways reconnect, while the brain is growing and developing. So, soon after Sebastian's diagnosis, Jocelyn Cote-Medeiros, an educator and family services coordinator at the Kennedy Donovan Center in New Bedford, helped Ms. Pereyra schedule intensive rehabilitative treatments and therapy for her son. The services were provided free of charge because Sebastian met health criteria set forth by the DPH's Early Intervention program guidelines.

Ms. Pereyra says Children's Hospital recommended Sebastian receive 25 to 30 hours of various therapies per week. Sebastian initially went to the Kennedy Donovan Center for early intervention a few mornings a week. Speech and occupational therapists went to his home and day care twice a week.

Children Making Strides, based in Bourne, provided in-home applied behavior analysis.

Still, in the first six months after Sebastian's diagnosis, the combined services added up to 12 hours per week, half of what doctors recommended.

"We had people coming and going all the time," says Mr. Oliva, who works a second shift, from 4 p.m. to midnight, in New Bedford's Industrial Park. Ms. Pereyra works days for a cell phone company in Bourne. The busy parents juggled work schedules so that Sebastian could get the home services he needed, but doing so became quite a logistical challenge.

"It was impossible," says Ms. Pereyra, recalling the frustration she felt in scheduling more therapy for her son. "I called and called and called until I got him the programs he needed. But, my doctor said he needed twice what he was getting. She said the more you get, the better you do for him."

In January, Sebastian enrolled in Carney Academy's Autism Spectrum Disorder program for 3- to 7-year-olds. Eight children are enrolled in this ABA-intensive class, which is designed to assist children who have a range of PDDs, including autism.

Sebastian now receives roughly the golden 30 hours of rehabilitation a week. While he is still largely non-verbal and has other developmental delays, Sebastian has learned to listen and stay on task with an activity, among other skills. His mother is very hopeful for his future.

"He's learned so much," says Ms. Pereyra. "In therapy, they first started Sebastian doing things for 20 seconds at a time. Then, they worked their way up to 20 minutes. It's just incredible."

"When I first learned his diagnosis, I thought I had to move to Boston to get the right therapy for him. But, Sebastian's doctor at Children's Hospital told me the program at Carney Academy is one of the best for autistic kids. I found out the best help is right here."

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