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Autism study offers hope

Disorder may be found in children 14 months old

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sun reporter

July 21, 2007

His mother suspected that there was something wrong, almost from the start. As an infant, Joshua Huffman kept to himself, didn't babble like most babies do, didn't respond to his name when called.

Three years later, Joshua is a whirlwind of activity who can put together puzzles with ease, race around his Clarksville house with older brother Zachary and even tell his brother, in very clear language, to go to timeout.

Joshua was part of a study at Baltimore's Kennedy Krieger Institute that revealed that half of children with autism can be diagnosed not long after the first birthday - nearly two years earlier than it has been reliably diagnosed before. Researchers, who still don't know exactly what causes autism, know this much: Early diagnosis leads to earlier intervention, which they hope can change the course of an autistic child's life, as happened with Joshua.

"It's a very significant finding, a very significant study," said Dr. Lisa Gilotty, chief of the social behavior and autism program at the Rockville-based National Institute of Mental Health which funded the research. "It speaks to the importance of early intervention ... before a child's development gets too far off course.

"She's showing us what to look for."

She is Dr. Rebecca Landa, the study's lead author and director of Kennedy Krieger's Center for Autism and Related Disorders. Landa has been conducting autism research for more than 20 years. She has been able to use her keen eye to spot the disorder earlier and earlier - this study showing the earliest yet. When Landa first started studying autism, she was working with children as old as 12. Then she realized she had to back up. "Where does it begin?" she wondered.

Autism is really a spectrum of disorders marked by impairment in social development and communication as well as by repetitive behaviors such as flapping arms or jumping up and down. Autistic children usually exhibit language delays and often have difficulties relating to

people, failing to read basic social cues in the faces of others.

The study, whose findings were published this month in the Archives of General Psychiatry, looked at 125 children from the age of 14 months until 36 months, most of whom were siblings of autistic kids.

Landa told her fellow researchers to make their best guesses at whether the 14-month-olds they observed were autistic or not, something they were reluctant to do. Half of those who were eventually diagnosed with autism could not be diagnosed that early because they appeared to be functioning like typical children. Only later did their development slow or regress.

In a conference room at Kennedy Krieger's Greenspring Avenue campus on a recent morning, Landa narrated a series of video clips taken of the children she studied. One showed a typically developing 14-month-old giggling away as he played with a toy and a therapist across the table. The boy was interested in the toy, to be sure, but seemed more enthralled with the woman, trying to get her to laugh with him.

Another showed Joshua at 14 months. A researcher tried to get him to play peek-a-boo with a blanket, but the boy was having none of it. He actually tried to get as far away as he could from the blanket and the person behind it.

Landa and her team can now spot many cases of autism from 14 months. The key now, she said, is to devise some guidelines for what parents and pediatricians should look for at that age to get the treatment started, trying to retrain the brain while it is at its most malleable. Researchers caution that not all children are equally successful with therapy. Specific therapies for this young age also need to be developed.

Up until now, Landa said, many pediatricians have pushed a wait-and-see approach if children don't meet milestones, thinking that they would grow out of their symptoms. This reassures many parents who don't want to believe the worst about their little ones.

Landa said parents with suspicions that something is wrong should insist on seeing an autism specialist. Sometimes it is difficult to get an appointment, she conceded, but she said Kennedy Krieger makes sure to see children under 2 within four weeks.

One in 150 children is estimated to have autism. This year, according to Kennedy Krieger, more children will be diagnosed with autism than AIDS, diabetes and cancer combined. Yet there is a dearth of professionals who can diagnose it and who can treat it, despite the surge of children who need help.

"We see an epidemic, but we don't yet have the resources to handle the epidemic," said Dr. Anthony L. Rostain, an associate professor of psychiatry and pediatrics at the University of Pennsylvania School of Medicine who studies developmental disorders. "We can't afford to wait."

Dr. Catherine Lord, director of the University of Michigan Autism and Communication

Disorders Center, said she wouldn't feel comfortable telling a family their child has autism at such a young age, but she would let parents know if she spotted red flags. "We don't want to be diagnosing everyone in the world with autism," she said. "But in almost all cases, the problem has been much more [that autism is] under-diagnosed."

Landa has funding to follow the children in her study - such as 3-year-old Joshua Huffman - until the age of 8.

The Huffmans' basement has been transformed into a miniature preschool, a place where Joshua and his 4-year-old autistic brother Zachary receive many hours of therapy a week. There have been play therapy, occupational therapy, speech therapy and specialized tutoring.

When Zachary was born, his mother, Ruth Huffman, took him to a playgroup with the women from her childbirth class and their babies, all girls. The girls blew all of the traditional milestones away. They crawled early, walked early, talked early. Zachary sat quietly in the corner.

Huffman knew something was wrong, but everyone told her he wasn't so far behind. When Zachary was a year old, a doctor suggested they "wait and see."

Zachary was diagnosed as autistic after his second birthday. By then he already had a little brother who was exhibiting many of the same signs. "I just remember crying, thinking, 'I can't do two,'" she recalled.

Soon, though, Joshua was in the Kennedy Krieger study. They started early intervention with him at 11 months, soon after the report arrived from Landa's researchers, stating what she already knew: Joshua was autistic.

The therapy has done wonders, she said. The kid in the video who was uninterested in a game of peek-a-boo now looks even visitors in the eye. His scores on language tests tell the same story. His ability to understand what he was being told was in the first percentile for kids his age.

Today, Joshua isn't symptom-free, but his language scores are in the 99th percentile. At 2, his brother spoke five words; at 2, Joshua spoke too many to count.

There is still work to be done. At an early age, Ruth Huffman said, she became "obsessed with having my child be able to communicate with me." She spent so much time making sure the words would come out that his social skills haven't kept up.

At age 4, her older son isn't doing as well as Joshua. But Zachary's progress has been remarkable as well. From a kid with almost no words two years ago, Zachary races to the door when a visitor arrives and asks, "What's your name?" Still, he is behind his brother - and may always be - because his treatment started 18 months later.

Huffman feels guilty about that. "If I had not taken that wait-and-see approach, he could have been that much closer to typical," she said.

"They don't have to be academic superstars. They don't have to be athletic superstars. My goal is for them to have friends."

Signs of autism:

In a study that identified autism in children as young as 14 months, Dr. Rebecca Landa and her colleagues at Kennedy Krieger's Center for Autism and Related Disorders identified the following signs of development disruption that parents and pediatricians should look for:

- Abnormalities in initiating communication with others -- rather than requesting help to open a jar of bubbles through gestures and sounds paired with eye contact, a child with autism may struggle to open it or fuss, often without looking at the nearby person.
- Compromised ability to initiate and respond to opportunities to share experiences with others -- autistic children will often miss cues that are important for engaging with others. For example, if a parent looks at a stuffed animal across the room, the child with autism often does not follow the gaze and look at the toy.
- Irregularities when playing with toys -- instead of using a toy as it is meant to be used, such as picking up a fork and pretending to eat with it, autistic children may repeatedly pick the fork up and drop it, tap it on the table or perform another unusual act with the utensil.
- Significantly reduced variety of sounds, words and gestures used to communicate.

[Source: Kennedy Krieger Institute]

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