

TRAPPED IN HIS OWN WORLD

by CHUCK BROWN

UNMC's Autism Center gives one
family hope.



Kyle Ohrt is 9 years old and can't speak a word.

He isn't toilet trained. He often cups his hands over his ears and rocks steadily or lets his hands compulsively move like a metronome.

One of his primary means of "communication" is to hit himself.

"And when I say he hits himself, I mean he really hits himself," said his mother Patti Ohrt. "He regularly leaves bruises on his face."

Kyle's hitting spells can last more than an hour. When one hand is restrained, he uses the other. When both are restrained, Kyle will bang his head on the ground.

Restraining Kyle is incredibly taxing, even for his father, Tom, an offensive lineman for the Nebraska Cornhuskers in the 1970s.

Kyle has severe autism and regularly wears a karate helmet and padded gloves to soften the self-inflicted blows. Kyle's plight seemed hopeless until he met Wayne Fisher, Ph.D., a world-renowned expert in treating children with severe autism.

Dr. Fisher, director of the autism spectrum disorders program at UNMC's Munroe-Meyer Institute, has given the Ohrt family hope.

Kyle was literally dropped into the Ohrts' life.

Nine years ago, the couple decided to adopt a child from third-world Romania.

"We've been fortunate," Ohrt said. "We've raised three girls and have done pretty well financially. We wanted to give someone a shot at a better life."

Throughout the adoption process, the Ohrts repeatedly were told Kyle was healthy and living in an orphanage. That was the story until they arrived in Bucharest – the nation's capital.



AUTISM SPECTRUM DISORDERS OFTEN LEAVE LOVED ONES OF THE SUFFERERS, AND THOSE TREATING THEM, PUZZLED. DR. FISHER'S RESEARCH HAS BROUGHT HOPE TO MANY.

THE AUTISM SPECTRUM

Autism and other disorders that share characteristics compose the Autism Spectrum.

CLASSIC AUTISM	PDD-NOS	ASPERGER SYNDROME	RETT'S SYNDROME	CHILDHOOD DISINTEGRATIVE DISORDER
<p>A developmental disability affecting communication and socialization. Common behaviors associated with autism are repetitive activities, resistance to changes of environment and erratic responses to sensory experiences. A lifelong condition that typically appears by age 3, autism has no known cure.</p>	<p>Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS) – Behaviors may resemble classic autism but may not be as severe. Also called mild or atypical autism.</p>	<p>Those with Asperger Syndrome have severe deficiencies in social skills. They struggle to read nonverbal cues and are often oversensitive to sensory experiences. Many with Asperger Syndrome exhibit exceptional talents in areas of interest.</p>	<p>This rare genetic disorder affects girls and includes neurological signs, such as loss of speech, incessant wringing of hands and seizures. Such behaviors become more apparent as the child ages.</p>	<p>Children with this disorder will appear normal for the first few years and then will regress, losing speech and other skills as the common behaviors associated with classic autism become dominant.</p>



“They told us he was in a foster home and that we could go pick him up,” she said. “Then the story changed – the foster parents were bringing Kyle to us. It was all very strange.”

The Ohrts were asked to wait for Kyle and his foster parents on a street corner in Bucharest. A short time later a car pulled up next to them and, in a split second, a passenger handed Kyle out of a window and into their arms, before speeding away.

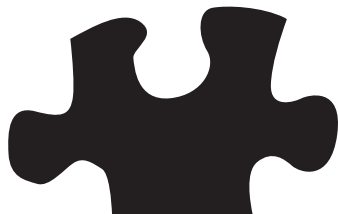
The suddenness of the transaction stunned the Ohrts, who were further jarred when a large truck clamored by seconds later.

Kyle didn’t budge.

“We thought he was deaf,” Ohrt said.

“That’s common with autistic children,” Dr. Fisher said. “The first thing many parents notice is the child isn’t responsive to sound – they think they’re deaf.”

Dr. Fisher arrived at UNMC last year. He was recruited to develop a world-class autism program similar to those he developed at the Kennedy-Krieger Institute at Baltimore’s Johns Hopkins University, where he spent 13 years, and most recently at the Marcus Behavior Center in Atlanta, which he formed in 1999.



Autism is a developmental disability stemming from a neurological disorder that disrupts normal brain function. Behaviors associated with autism range from difficulty expressing needs and a need for similarity to repeating words and phrases, obsessive attachment to certain objects and self abuse.

The self abuse, Dr. Fisher said, is how many autistic children express themselves, especially if they hear a sound they don’t like, are exposed to colors that bother them or are in a situation they don’t find comfortable. The children know that hitting draws immediate reaction from those around them, Dr. Fisher said.

“While indeed harmful, the behavior is functional,” he said.

The spectrum of autistic behaviors extends from an inability to make eye contact, unresponsiveness to instruction and over or under sensitivity to pain and noise. Kyle exhibits many of these behaviors.

Curing these behaviors is not the goal. Dr. Fisher and his team want to understand what causes them.

“We examine the social and environmental factors that lead to this behavior and then develop ways around and through those behaviors,” Dr. Fisher said.

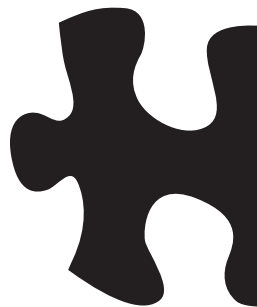
Understanding behaviors to design treatment remains a major point of Dr. Fisher’s research. It’s this approach that allowed him to become a forerunner in autism treatment, said Chris Bullock, Ph.D., a post doctorate research associate who is part of Dr. Fisher’s team.

“Instead of simply trying to stop the patient’s behavior, which was the standard care before, he examines the cause and begins treatment at that level,” Dr. Bullock said.

Here’s an example of how it works:

An autistic child holds a ball in his hand with no intention of letting go.

He has work to do with Dr. Fisher’s team – a learning exercise – but he’s not interested. He aggressively rejects any attempt by team members to take the ball from him or get him to do the exercise.



PATTI OHRT PLAYS WITH HER SON, KYLE, AT UNMC'S NEW AUTISM FACILITY.



The boy is given a simple choice: either do the work with ball in hand or give it to a team member.

Ball in hand, the boy completes the learning exercise.

These little steps give Dr. Fisher and his team a foothold, allowing for more breakthroughs.

“We find what motivates these kids and use it to tailor an environment to suit them,” Dr. Fisher said.

Children who work through Dr. Fisher’s program average a 15-point increase in IQ scores and most show drastic reductions in many of their autistic behaviors, he said. For many, that translates into a fairly typical life.

“With many patients, the goal is to get them to function as normal as possible,” Dr. Fisher said. “We want them to be able to sit in class and follow instruction like other children. That’s a big, big change and we do accomplish that here – not with everyone – but with many.”

Dr. Fisher’s arrival at UNMC was a godsend for the Ohrt family. With no comprehensive program in the region, the Ohrts made due with whatever help they could find locally.

That included a long list of in-home specialists and technicians, as well as autism programs in the area.

Two years ago, a local specialist told the Ohrts they had exhausted local treatment options and they should consider moving to Maryland so Kyle could enter the program Dr. Fisher developed at Johns Hopkins.

Family and financial concerns made that move seem impossible. Besides, Ohrt said, Omaha was home.

Then, the Ohrts heard Dr. Fisher was coming to UNMC.

Today, Dr. Fisher and his team practice at the Munroe-Meyer Institute, where space has been renovated to meet the needs of the program.

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Dr. Bullock, who came to Nebraska from Florida just to mentor under Dr. Fisher, spends two afternoons a week in the new facility with Kyle.

Together, they work on reducing self-harming behavior, improving toilet training and developing a communication system that involves Kyle pointing at items he wants.

Kyle’s autism is such that he will not be able to function normally as some of Dr. Fisher’s other patients will. That doesn’t mean he won’t make significant progress.

In fact, progress already has been made in the past year under Dr. Fisher’s care.

Kyle, who attends special education classes at an Omaha-area grade school, has had entire days at school during which he hasn’t hit himself. That was almost unheard of before Dr. Fisher’s arrival, Ohrt said.

Ohrt knows the day is coming when she and her husband will not be able to physically deal with Kyle. He’ll simply be too strong. Dr. Fisher’s program brings hope that he’ll eventually be able to live in a group home.

Ohrt has one additional goal.

“My greatest dream,” she said, wiping away tears, “is that one day he’ll be able to look at me and call me ‘Mom.’” 