



A preschool-style program at Kennedy Krieger has helped Owen Skerry, left, start to communicate.

Photography by Brett Ziegler for *USN&WR*



An All-Out Assault on Autism

IT'S INTENSIVE, STARTS EARLY, AND DEPLOYS A WHOLE TEAM

BY MICHAEL MORELLA

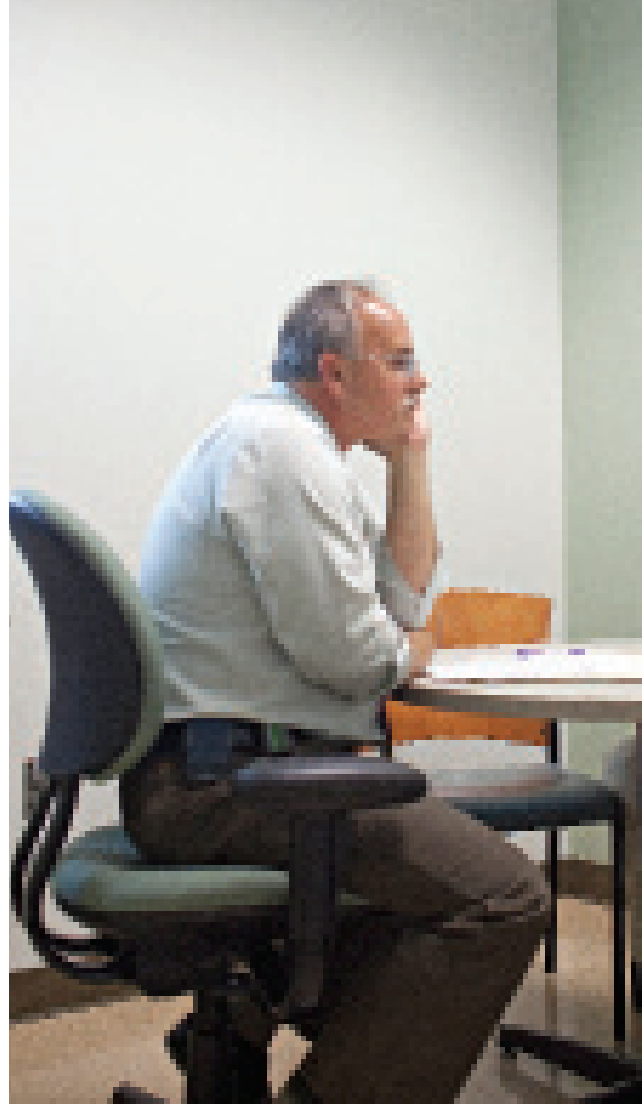


At 18 months, Colton Rose was shy and a little late in walking but seemed to be progressing fine—laughing, smiling, talking. Several months later, however, his mother Angela started to worry. He was talking less and less, didn't engage with others as much, and hadn't yet

started using a spoon or taking off his own shoes. "He kind of started slipping more and more into his own world," says Rose, a former marketing and communications manager. Sure enough, shortly after turning 2, Colton was diagnosed with autism. Yet a mere 15 months later, says Rose, "he's an entirely different child."

Soon after Colton's diagnosis, the toddler began intensive treatment through Nationwide Children's Hospital in Columbus, Ohio, near home. Each week, he receives 35 hours of behavioral therapy, sometimes at home and sometimes at preschool. It breaks tasks like asking for food into steps (point to ice cream, say "ice cream," request some politely), encourages him to imitate the steps, and reinforces the behaviors with rewards and encouragement. His mother, now a "full-time autism mom," practices with him for several hours a day herself and has weekly planning sessions with a Nationwide case supervisor and Colton's team of five aides. The family also meets periodically with a psychologist to track Colton's developmental progress. And it's good. In many ways, he's now "in a total normal category," says Rose. He's made impressive gains in social skills and is testing at or above average for speech.

Nationwide's approach to treatment demonstrates per-



haps the best hope for children with an autism spectrum disorder: starting early—even as young as 12 months—and deploying a team of experts, from neurologists and physical therapists to psychologists and gastroenterologists, to tackle any aggravating issues. The latest research, which has taken on heightened urgency as estimates of prevalence have risen (in March, the Centers for Disease Control and Prevention put the rate at 1 in 88 children, up from 1 in 110 two years earlier), indicates that early intervention can make a big difference in cognitive and communication skills, language development, and anxiety and aggressiveness. Many such programs, including Colton's, are based around 25 to 40 hours a week of Applied Behavior Analysis, which lasers in on teaching specific behaviors using repetition and rewards.

A number of drug treatments, too, are suddenly showing promise at improving some symptoms. And many clinicians are finding that managing conditions commonly associated with autism, like epilepsy and gastrointestinal distress, can significantly improve behavior and allow other treatments to have a greater impact. Parents can address "whole body" issues by improving a child's diet, reducing exposure to potentially harmful chemicals, and eliminating stressors, suggests Martha Herbert, an assistant professor of neurology at Harvard Medical School and author of the new book *The Autism Revolution*. "If we could reduce the overwhelm" of other conditions, she says, "then we might not have so much of this."

While autism's causes remain a mystery, it's now widely believed that the symptoms result from a combination of genetics—perhaps involving hundreds of genes—and environmental factors around the time of conception or birth, such as advanced parent age and living near a freeway, that might affect brain development and function. The CDC reports that currently most kids aren't diagnosed until age 4, though researchers and clinicians agree that the earlier treatment starts, the better. "Basically, as soon as you can get in there and do it," advises Fred Volkmar, director of the Yale Child Study Center in New Haven, Conn., who notes that autism's effects appear to be cumulative. A 2011 review of treatment studies over the previous decade found that the most effective interventions are intensive and start as young as age 2; data on children younger than that, though preliminary, were "promising." Brain development "is really a very plastic process," says Sally Rogers, professor of psychiatry and behavioral sciences with the MIND Institute at the University of California–Davis. "Experiences across your life, but particularly in the first five years, actively sculpt the brain."

An early start. Rogers has gathered some of the promising preliminary data. With Geraldine Dawson, a professor of psychiatry at the University of North Carolina–Chapel Hill and chief science officer of the research and advocacy organization Autism Speaks, she developed a program called the Early Start Denver Model that combines one-on-one Applied



Mass General's one-stop shop (clockwise from upper left) • Gabriel Silverstein, 3, receives occupational therapy • Alexander Dangel, 14, and his mother Betsy get a GI consult • Kevin Heaney, 17, works on his speech skills.

for small groups of 2-year-olds involves about 10 hours of therapy a week in a preschool format—play time, circle time, snack time—plus practice at home. “It’s so much more than a cute little classroom,” says Rebecca Landa, director of Kennedy Krieger’s autism center. Her research has shown that the children make impressive strides in cognitive skills and social abilities like imitation and shared attention. “They make 11 months’ gain in six months in their language development,” she says. Kennedy Krieger researchers are now examining programs for 1-year-olds. “It gives you hope,” says Kristen Skerry, a former school counselor from Lutherville, Md., whose son Owen, now 3, enrolled in September, when he wasn’t talking and simply cried when therapists came to his home. Now he communicates, often through gestures, makes eye contact, and pays attention to tasks.

Nationwide Children’s and Kennedy Krieger are two of 17 medical centers in the United States and Canada that make up the Autism Treatment Network (ATN), a group of institutions recognized by Autism Speaks for comprehensive care involving all sorts of specialists. About half of children with an autism spectrum disorder also

Behavior Analysis treatment with a more natural play-based therapy for children just 12 months old. A study the two published in 2009 in *Pediatrics* found that after two years of the treatment, a group starting at ages 18 to 30 months showed an average IQ jump of more than 17 points, versus 7 points in toddlers who received other services. They also demonstrated higher scores in language, daily living, and motor skills.

An Early Start therapist uses a child’s own toys and regular play activities, at home, to work on learning goals, such as passing a ball to the child and throwing it in a bucket so the child follows suit, for example, to work on attention, imitation, motor skills, and social interaction. All the while, the therapist uses gestures and repeats the word “ball” to work on communication. “Everything is a tool that you can use to teach them,” says Rashelle Lawson, a property manager in Sacramento, Calif., whose son Preston received 2½ years of Early Start therapy after he was diagnosed with autism at 18 months. Beforehand, Preston, now 6, had stopped speaking and would scream when touched. “Now he’s a love bug,” says Lawson. Preston is enrolled in a regular kindergarten class with his own aide.

Researchers at the Kennedy Krieger Institute in Baltimore, a hospital that serves children with developmental disabilities and brain disorders, are seeing promise in early classroom-style intervention, too. Their six-month program

have at least one of several associated conditions, such as attention deficit hyperactivity disorder, an intellectual disability, or epilepsy; more than 40 percent have sleep problems. Besides helping families live more comfortably with autism, treating these medical problems often helps kids respond better to therapy, experts say. It “has paid off in spades,” says Margaret Bauman, a pediatric neurologist at Massachusetts General Hospital for Children in Boston.

Under one roof. Mass General operates its own ATN site, the Lurie Center for Autism, in Lexington, about 20 miles from the hospital’s Boston campus. Under the same roof, autistic children and adults can be evaluated by a neurologist and developmental pediatrician, treated for stomach problems by a gastroenterologist, and examined for possible mental illnesses by a psychologist or other specialist. Parents can meet with an education specialist or resource coordinator to manage outside services, and patients can receive speech, physical, and occupational therapy at an outpatient rehab center on the premises. During the summer, children through age 15 can attend a hospital-sponsored seven-week day camp nearby that integrates therapy with swimming, art, and hiking.

Teens and young adults get recreational outings and can participate in weekly social skills groups that deal with topics like flirting and dating, making small talk, and preparing for the workforce. “We really tried to make this sort of a one-stop



shop,” Bauman says. Because most people with autism are affected their entire lives, many parents and experts say that providing transitional services for teenagers and adults is critical.

“One person led us to another led us to another,” says Joellyn Boggess, of Paducah, Ky., whose daughter Erin, 9, has been receiving coordinated care at Vanderbilt University Medical Center in Nashville, also an ATN facility, even though it’s about 140 miles from home. One sleep study led to supplements of melatonin, a naturally occurring hormone that regulates the body’s circadian rhythms. Because Erin was having some staring spells, a neurologist investigated and found complex partial epilepsy; medication has since improved her attentiveness. A GI specialist suggested a high-fiber diet and medication. This summer, the family is moving to Nashville, where Boggess’s husband, a social worker, was able to find a job at a Veterans Affairs hospital.

Imaging inroads. Eventually, researchers hope that imaging brains of people with autism and their siblings might help identify biomarkers that predict which children will be affected and even where on the spectrum they might fall. (Brothers and sisters of individuals with autism have much higher than average odds, about 1 in 5, of developing the disorder.) In people with autism, nerve cells connecting regions of the brain appear to develop and function differently. “It’s the connections that really make it all work,” says Helen Tager-Flusberg, a professor of psychology at Boston University and president of the International Society for Autism Research. A neuroimaging study of infants at risk for autism released in February revealed differences in the development of white matter, across which signals in the brain are transmitted, in those who went on to develop autism and those who did not. Some of the differences were visible even at 6 months of age.

By pinpointing the ways in which the brain works differently,

Luke Rosas, 21, checks his motor skills with his doctor, Mass General’s Susan Connors.

researchers can also try to develop drug treatments that address the core features of autism, says Robert Schultz, coauthor of the neuroimaging study and director of the Center for Autism Research at the Children’s Hospital of Philadelphia, also an ATN site. Currently, there are no drugs available that do so. But a number of medications show promise against poor social functioning and communica-

tion. Preliminary results from Yale have indicated that giving supplements of the social bonding hormone oxytocin, for instance, boosts activity in parts of the brain related to social interaction. And several drug treatments for one known genetic cause of autism, Fragile X syndrome, are now entering clinical trials and could one day treat autism more broadly. Seaside Therapeutics, in Cambridge, Mass., has developed a compound that seeks to regulate a brain cell pathway that appears out of balance in Fragile X and leads to socially avoidant behaviors. In a test of 27 socially avoidant individuals with Fragile X, more than 40 percent demonstrated significant improvement in social behavior while on Seaside’s drug versus about 7 percent on a placebo, says Paul Wang, a developmental pediatrician and vice president of clinical development at Seaside. “We got stories of kids who now hung out in the kitchen with their mom instead of just holing up in their room,” he says.

Meanwhile, researchers at Mount Sinai School of Medicine in New York have begun testing a protein called insulin-like growth factor 1 in people affected by a mutation of the SHANK3 gene, also a cause of autism spectrum disorders. Tests in mice with the mutation have shown that affected communication deficits in the animals’ brains, particularly those related to learning and memory, appeared to correct themselves. “If you can have medication that targets the core symptoms of autism,” says Alison Singer, president of the Autism Science Foundation, a nonprofit organization focused on research, “to me that’s the holy grail.” ●