

MIND

Desperate for an Autism Cure

Diagnoses have soared, but valid treatments are few. Parents have turned instead to dubious, and often risky, alternative therapies

By Nancy Shute





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WHEN JIM LAIDLER'S OLDEST son, Benjamin, was diagnosed with autism, he and his wife started looking for help. "The neurologists were saying, 'We don't know what causes autism, and we don't know what the outcome for your son will be,'" Laidler relates. "No one was saying, 'Here's what causes it; here's what treats it.'"

But when the Laidlers, who live in Portland, Ore., searched the Web, they found dozens of "biomedical" treatments that promised to improve or even cure Benjamin's inability to talk, interact socially or control his movements. So the parents tried them on their son. They began with vitamin B₆ and magnesium, the nutritional supplements dimethylglycine and trimethylglycine, vitamin A, gluten- and casein-free diets, the digestive hormone secretin, and chelation, a drug therapy designed to purge the body of lead and mercury. They applied the purported treatments to Benjamin's little brother, David, who also was diagnosed with autism. Chelation did not seem to help much. Any effect from secretin was hard to tell. The diets showed promise; the Laidlers hauled special food with them everywhere. And Mom and Dad continued to feed the boys dozens of supplements, calibrating doses up and down with every change in behavior.

IN BRIEF

Fringe frenzy: As many as 75 percent of autistic children are receiving alternative treatments not developed by conventional medicine, which are often bogus.

Risky medication: Some practitioners prescribe drugs that are approved only for other conditions, have serious side effects and have never been tested for safety or efficacy in autism.

More science: In the past decade U.S. research funding for autism has increased by 15 percent a year, in part because of rising demand by parents for proved treatments and increased public awareness.

Genetic promise: Recently discovered genetic variations in children with autism could reveal a cause, but related therapies may be years away.

The first sign that their experiments had failed came when Laidler's wife, who had become increasingly skeptical, quit giving Benjamin supplements. She waited two months before telling her husband. Her silence ended the day Benjamin grabbed a waffle off a buffet during a family trip to Disneyland and wolfed it down. The parents watched with horror, convinced that he would regress the instant he went off his restricted diet. He didn't.

Jim Laidler should have known better. He is an anesthesiologist. He was aware from the beginning that the treatments he was using on his children had not been tested in randomized clinical trials, the gold standard for medical therapies. "At first I tried to resist," he says. But hope won out over skepticism.

Hundreds of thousands of parents every year succumb to the same desire to find something—anything—that might alleviate the symptoms of their struggling sons and daughters: lack of speech and communication, inept social interactions, repetitive or restrictive behaviors such as hand flapping or fixating on objects. As many as 75 percent of autistic children are receiving "alternative" treatments not developed by conventional medicine, according to some studies. And yet the therapies are often bogus. They have not been tested for safety or effectiveness, they can be expensive, and some of them may actually do harm. Fortunately, recent spikes in autism diagnoses and parent activism are pushing more federal and private funding toward research that could someday yield scientifically proved results.

Solid, scientific research simply does not exist for many autism treatments, and where it does, the number of children studied is often small.

NO CAUSE, NO CURE

THE DEMAND FOR AUTISM TREATMENTS is rising largely because more children are being diagnosed under broader criteria. Back in the 1970s, when autism was called "infantile psychosis"—a mix of social deficits and mental retardation—the condition was considered rare. Pediatricians would tell parents who were worried that, say, their eight-month-old wasn't making eye contact, to wait and see.

Studies indicated that about five children in 10,000 had autism, but the rate grew higher when doctors redefined the condition as autism spectrum disorder, which included milder symptoms. By the time an updated version of psychiatry's bible, the *Diagnostic and Statistical Manual of Mental Disorders*, known as the *DSM*, was published in 1994, doctors had added Asperger's syndrome—a high-functioning form popularized in the movie *Rain Man*—and a catchall group termed "pervasive developmental disorder, not otherwise specified." Doctors also started realizing the benefits of early diagnosis and treatment. In 2007 the American Academy of Pediatrics recommended universal screening of all children for autism between 18 and 24 months. By then, the autism rate had shot up to one in 110 children.

Whether greater diagnoses reflect a true rise in cases is a matter of controversy, because little is known about what causes the condition. "For the large majority of people with autism, we don't even know a clear-cut genetic factor," says David Amaral, research director of the MIND Institute at the University of

California, Davis, and president of the International Society for Autism Research. No biomarkers are available to tell which children are at risk or to gauge how well treatments work. The greatest body of research is on behavioral interventions designed to teach social interaction and communication, which appear to help some children to varying degrees.

The lack of empirically vetted therapies makes it far easier for sellers of untested treatments to market hope. "What you've got is a combination of pseudoscience and fraud," says Stephen Barrett, a retired psychiatrist in Chapel Hill, N.C., who reports on dubious medical treatments at his Web site Quackwatch.com. "Parents are under a great deal of stress. They so want their kid to be better. They see improvement over time, and they give credit to the wrong thing." Those gains are not because of the "treatment," he says, but because children mature as they age.

Snake-oil salesmen litter the Web. One site tells parents they can "defeat the autism in your child" by buying a \$299 book; another touts a video of "an autistic girl improving after receiving stem cell injections." Many parents acknowledge that they get their information from the Internet, and "a lot of parents rely on anecdotal reports, friends or other parents," says Brian Reichow, an associate research scientist at the Yale Child Study Center. "In autism, the research has not caught up with the treatments."

Hope doesn't come cheap, either. Alternative treatments such as lying in a pressurized, hyperbaric oxygen chamber (used to overcome compression sickness), which temporarily increases blood oxygen levels, cost \$100 an hour or more, with one to two hourly sessions recommended daily. Sensory integration therapy, which can range from wrapping children in blankets or placing them in a hug machine to having them play with scented clay, can cost up to \$200 an hour. Purveyors charge as much as \$800 an hour for consultations and thousands more for vitamins, supplements and lab tests. Parents in an ongoing survey by the Interactive Autism Network at the Kennedy Krieger Institute in Baltimore report spending an average of \$500 a month out-of-pocket. The one treatment for autism that has been proved to be somewhat effective—behavioral therapy—can also be the most expensive, at \$33,000 or more a year. Although state early-intervention programs and public school districts often cover these costs, the wait for free evaluations and services can be long. All told, direct medical and nonmedical costs for autism add up to an average of \$72,000 a year, according to the Harvard School of Public Health.

MEDICAL SNAKE OIL

UNPROVED THERAPIES extend to medications. Some practitioners prescribe drugs approved for other illnesses. The compounds include Lupron, which blocks the body's production of testosterone in men and estrogen in women; it is used to treat prostate cancer and to "chemically castrate" rapists. Doctors also have prescribed the diabetes drug Actos and intravenous immunoglobulin G, usually used for leukemia and pediatric AIDS. All three medications have serious side effects and have never been tested for safety or efficacy in autism.

Chelation, the primary treatment for lead poisoning, is another legitimate medical therapy turned autism "cure." The drug converts lead, mercury and other metals into chemically inert compounds that the body can excrete in urine. Some people think exposure to such metals, particularly the methylmercury used as a preservative in vaccines, can cause autism, even

Dubious Therapies



though no studies have demonstrated such a link. Indeed, autism diagnosis rates continued to climb after methylmercury was phased out of most vaccines in 2001. Chelation can cause kidney failure, particularly in the intravenous form favored for autism. In 2005 a five-year-old boy in Pennsylvania with autism died after being given intravenous chelation.

Concern led the National Institute of Mental Health to announce plans in 2006 for a randomized, controlled trial of chelation for autism. But the institute shelved the study in 2008 because officials could find “no clear evidence for direct benefit,” and the treatment put the children at “more than a minimal risk.” Their worry arose in part from lab studies that showed cognitive problems in rats that received chelation and did not have metal poisoning. “I don’t think anybody had much faith that chelation would be the answer for a large number of children,”

says Thomas R. Insel, director of the NIMH. His researchers, he adds, are “more interested in testing medications that have a mechanistic basis.”

Predictably, the abandoned study fueled charges that Big Science was ignoring alternative treatments. Money has always flowed more to discovering cures that work than to discrediting ones that don’t. Until very recently, most autism research has been conducted in the social sciences and special education fields, where research budgets are modest and protocols are far different than medicine’s. At times only a single child is involved in a study. “We would not even call it evidence,” says Margaret Maglione, associate director of the Southern California Evidence-Based Practice Center at RAND, who is leading a federally funded review of behavioral treatments that will be published in 2011.

MANY HAYSTACKS, FEW NEEDLES

STATE-OF-THE-ART SCIENTIFIC RESEARCH simply does not exist for many autism treatments, and where it does, the number of people studied is often small. In 2007 the Cochrane Collaboration, an independent evaluator of medical research, reviewed casein- and gluten-free diets, which are based on the premise that compounds in casein, a milk protein, and in gluten, a wheat protein, interfere with receptors in the brain. Cochrane identified two very small clinical trials, one with 20 participants and one with 15. The first study found some reduction in autism symptoms; the second found none. A new, randomized, controlled trial of 14 children, reported this past May by Susan Hyman, an associate professor of pediatrics at the University of Rochester School of Medicine and Dentistry, found no changes in attention, sleep, stool patterns or characteristic autistic behavior. “Slowly the evidence is starting to accumulate that [diet] is not the panacea people are hoping for,” says Susan E. Levy, a pediatrician at Children’s Hospital of Philadelphia who has evaluated the evidence with Hyman.

Levy has firsthand experience with the level of effort needed to sway public opinion. Secretin became a hot commodity after a 1998 study reported that three children had better eye contact, alertness and use of expressive language after being given the hormone during a diagnostic procedure for gastrointestinal problems. Media outlets, including *Good Morning America* and *Ladies’ Home Journal*, recounted parents’ joyous tales of children transformed. The National Institute of Child Health and Human Development rushed to fund clinical trials. By May 2005 five randomized clinical trials had failed to reveal any benefit, and interest in secretin waned. It took years for that to play out, says Levy, who helped conduct several of the trials: “Research is very labor-intensive, and progress may be slow.” Parents may feel helpless, she adds, and “they don’t want to leave any stone unturned.”

The good news is that rising demand for proved treatments is attracting money for research. When the first International Meeting for Autism Research was held in 2001, barely 250 people attended. This past May 1,700 researchers, graduate students and parent advocates showed up for the meeting in Philadelphia. New technologies and increased public awareness have helped make autism a more appealing research focus. And in the mid-1990s

parents began adopting the sophisticated lobbying and fund-raising tactics used for AIDS and breast cancer, leaning on foundations and the federal government.

As a result, in the past decade U.S. research funding for autism has increased by 15 percent a year, with an emphasis on clinical applications. The National Institutes of Health allocated \$132 million for autism work in 2009, with an additional \$64 million from the American Recovery and Reinvestment Act, much of which is being earmarked to develop patient registries and other investigative tools.

Behavioral therapy—the one treatment that has been proved to be somewhat effective—can be the most expensive, at \$33,000 or more a year.

Private foundations, including the

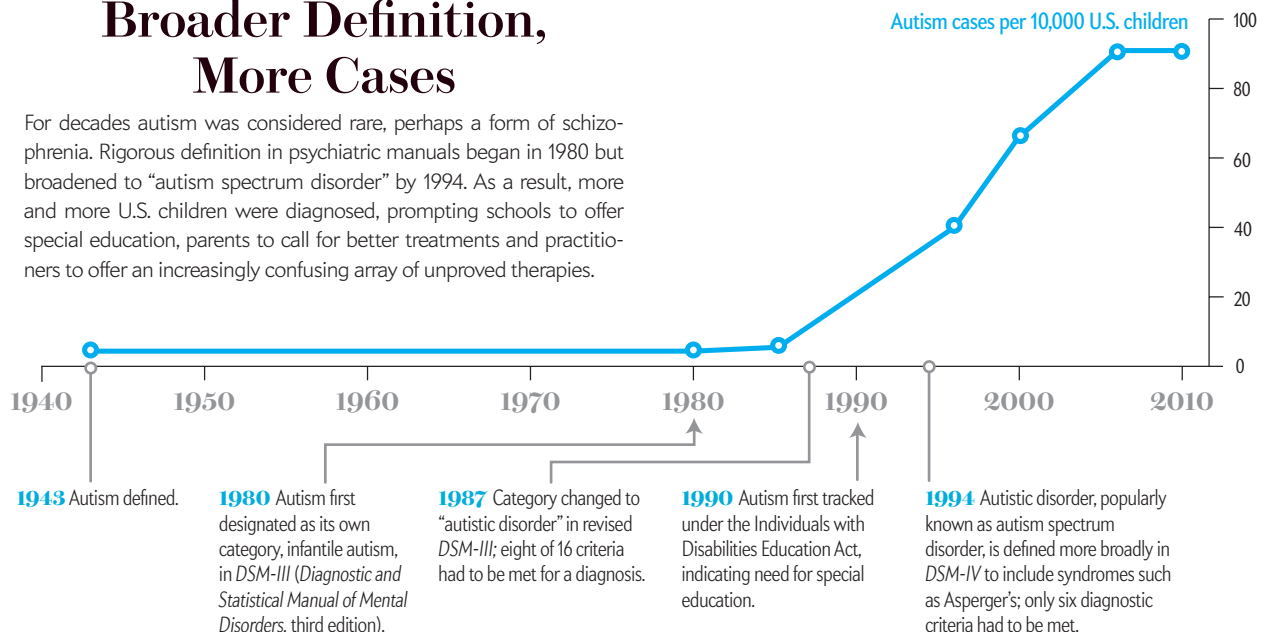
Simons Foundation and Autism Speaks, contributed \$79 million in 2008. According to Autism Speaks, about 27 percent of all funding is being spent on investigating treatments, 29 percent on causes, 24 percent on basic biology and 9 percent on diagnosis.

These new pursuits encompass efforts to find out if early intervention with behavioral therapies that teach children social skills through repetition and reward can be used successfully with children when they are very young, when the brain is in the

DIAGNOSES

Broader Definition, More Cases

For decades autism was considered rare, perhaps a form of schizophrenia. Rigorous definition in psychiatric manuals began in 1980 but broadened to “autism spectrum disorder” by 1994. As a result, more and more U.S. children were diagnosed, prompting schools to offer special education, parents to call for better treatments and practitioners to offer an increasingly confusing array of unproved therapies.



SOURCES: U.S. CENTERS FOR DISEASE CONTROL AND PREVENTION; AMERICAN PSYCHIATRIC ASSOCIATION

thick of learning language and social interaction. A study by several universities, released online in November 2009, found that children who were given two years of behavioral therapy for 31 hours a week, starting when they were between 18 and 30 months old, made substantial gains in IQ (17.6 points, compared with 7 points in the control group), and in skills of daily living and language. Seven of the 24 children in the treatment group improved enough that their diagnosis was upgraded from autism to the milder “not otherwise specified” form; only one child in the 24 who were given other interventions was given a milder diagnosis. The Autism Treatment Network has built a registry of more than 2,300 children for research on treatments for medical complications often suffered by autistic children, especially gastrointestinal issues and difficulty sleeping, and it plans to develop guidelines that could be used by pediatricians nationwide.

TOWARD A TRUE SCIENCE OF AUTISM

EFFORTS TO FIND MEDICATIONS, including those used in other neurological disorders, may have higher hurdles to clear. Medical interventions have been “a bit of a disappointment,” Insel says. For example, antidepressants that boost the neurotransmitter serotonin in the brain are very effective in reducing the repetitive hand motions of obsessive-compulsive disorders, but a review by the Cochrane Collaboration reported in August that the drugs did nothing to alleviate the repetitive motions typical of autism. Among the new candidates are a medication that enhances REM sleep, which is lacking in children with autism, and oxytocin, a hormone that promotes childbirth and lactation and is thought to encourage mother-infant bonds. A study published in February by the National Center for Scientific Research in France found that 13 teenagers with Asperger’s were better at identifying images of faces after inhaling oxytocin. A big leap would have to be made between that one study and the notion that oxytocin could mitigate autism’s most devastating symptoms. Insel says: “We have a lot of work to do.”

That work is starting to be done. In June a consortium of researchers who scanned the genes of 996 grade-schoolers found rare, novel genetic variations in children with autism. Some of the glitches affect genes that control communication across synapses—the contact points between neurons in the brain, a key focus of autism inquiries. “The actual mutations are different [among individuals], but there may be some commonalities in the biological pathways,” says Daniel Geschwind, a professor of neurology and psychiatry at the David Geffen School of Medicine at U.C.L.A., a study leader. Geschwind is also a founder of the Autism Genetic Resource Exchange database of DNA samples from more than 1,200 families with autism, which was used in the study. Tests to confirm a culprit, or treatments that might fix the glitch, are still years away.

For now, more parents may be choosing not to experiment, if only so they can sleep at night. Michael and Alison Giangregorio of Merrick, N.Y., decided when their son, Nicholas, was diagnosed at age two that they would use only evidence-based treatments such as applied behavioral analysis. “It’s difficult



Jim Laidler calls current therapies “shamanism” but tried them on his sons anyway, out of desperation.

enough and challenging enough to help my son,” Michael says. “I was not willing to try experimental therapies. I need to do what clinicians and researchers have taken the time to prove works and to prove that it doesn’t do any additional harm.” Nicholas is now nine, and although he remains nonverbal, behavioral therapy has taught him to use physical signals when he needs to go to the bathroom. He can now wash his hands, sit through dinner in a restaurant and walk down an aisle in the drugstore without flapping his hands. “Obviously, the goal of my family, and most families, is to lead as normal a life as possible,” says Michael, a 45-year-old Wall Street trader. “Normal is going out to dinner as a family.”

Jim Laidler’s path to the same place was far more crooked. Although he embraced alternative treatments for his sons, he also tried to persuade practitioners that they needed to apply the rigor of mainstream science in evaluating such options. “I kept harping on it. Did you do any controls?” he says. His oldest son, now 17, will probably never be able to live on his own, yet his younger son is in a regular middle school. Of the many treatments the family tried, Laidler, 51, says: “This is basically shamanism in a lab coat.” Thousands of desperate parents are hoping that science will one day offer stronger medicine. ■

MORE TO EXPLORE

Autism Genetic Resource Exchange, an open-access registry of DNA from families with autism: www.agre.org

Autism Speaks advocacy group, funded research: www.autismspeaks.org/science/science_news/index.php

U.S. Centers for Disease Control and Prevention overview of research and parent information: www.cdc.gov/ncbddd/autism/index.html

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