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Autism Therapies Still a Mystery, but Parents Take a Leap of Faith

By **BENEDICT CAREY**

Desperate parents of autistic children have tried almost everything - hormone injections, exotic diets, faith healing - in the hope of finding a cure.

But more than 60 years after it was first identified, autism remains mystifying and stubbornly difficult to treat. About the only thing parents, doctors and policy makers agree on is that the best chance for autistic children to develop social and language skills is to enroll them in some type of intensive behavioral therapy.

A government-appointed panel has endorsed such therapies, which can cost \$40,000 to more than \$60,000 per year. Parents fight to get their children placed in behavioral programs, encouraged by the claims of some therapists that they can produce astonishing improvement in up to 50 percent of cases. An estimated 141,000 children with autism receive special education services, in many cases including behavioral therapies, through public schools.

Yet the science behind behavioral treatments is modest at best. Researchers have published very few rigorously controlled studies of the therapies, and the results of those studies have been mixed. While some children thrive, even joining regular classrooms, the studies have found that most show moderate or little improvement. And researchers say most parents now experiment with so many alternative treatments - including vitamins, diets, sensory therapies and computer games - that they muddy the results of behavior treatment, making it very hard to say what is causing a child to gain skills or to decline.

The most recent analysis of treatment research, financed by the National Institutes of Health and scheduled to be published next year, concludes that although behavior treatments benefit many children, there is no evidence that any particular treatment leads to recovery. Doctors do not yet know how to predict which children will improve in the treatments, or even how treatable the condition is, the report concludes.

"If so many kids are being cured, then where are they? Who are they? Show me 10 percent," said Dr. Bryna Siegel, director of the autism clinic at the University of California, San Francisco. "The reason practitioners can't show you all these kids is because there simply aren't that many of them out there."

Questioning the Evidence

No one disputes that behavioral therapies can be transforming: parents are deeply committed to them, and most experts emphasize their successes, saying that they are the best option now available.

But others say the evidence is not as solid as it is sometimes made out to be - a view echoed by some health insurers, who have refused or limited coverage for treatment. And politics, the experts say, sometimes gets in the way of a frank evaluation of how well the programs work.

"We're at a point," said Dr. Susan Hyman, an associate professor of pediatrics at the University of Rochester Medical Center, "where questioning the evidence behind them is like criticizing your grandmother's matzo-ball soup."

Behavioral treatment programs come in several varieties. A therapy called applied behavior analysis is the most studied and most commonly used. In this approach, the therapist begins by working one on one with a child, often 20 to 40 hours a week, to build social and language abilities in very small steps - by rewarding the youngster with a treat for learning words, for example, or for sitting still or greeting someone.

A state-financed program in North Carolina, known by the acronym Teacch (its full name is Treatment and Education of Autistic and Related Communication Handicapped Children), uses pictures and schedules, among other techniques, to keep children focused and interacting with others, and to take advantage of their visual skills. It is taught in classrooms, by trained teachers, or in special clinics, and is provided free throughout the state.

Floor Time, another popular option, has teachers and parents on the floor, following a child's lead in interactive play to develop emotional connections. Other approaches, including the Denver Model and Pivotal Response Training, blend rewards for specific behaviors with play techniques and schedules. These have also helped children improve.

In a 2001 report, a National Academy of Sciences panel convened by the federal government evaluated all the research and concluded that treating children as early as possible, and giving them at least 25 hours a week of therapy, was more important than the specific name-brand approach used. Parents' involvement in the treatment was especially helpful, the report said.

In some states, parents have fought legal battles with school districts to get such programs paid for. Many parents hire therapists to come to their homes; others move to other states to get better services.

"We redesigned our entire third floor to look just like the Teacch classroom," said Inga Sawyer, whose 5-year-old son and 3-year-old daughter use Teacch methods in Carrboro, N.C., near Chapel Hill. "Both of them thrive on the structure, and it has been really

helpful in organizing their day" and mainstreaming them in school, she said.

Belief Versus Proof

But believing in the programs is one thing; proving how well they work is another. Researchers say traditional studies are difficult to carry out. The therapies are extremely time-consuming, and some parents, unwilling to take a chance on less-than-optimal therapy, refuse to let their children be part of the control groups that are essential for scientific research. Even the most well-known and rigorously studied brand of behavioral therapy, the Lovaas method, appears to be less effective than was originally hoped, and its record in studies is mixed.

Named after its inventor, Dr. O. Ivar Lovaas, a psychologist at the University of California, Los Angeles, the method is taught from manuals and is a version of applied behavior analysis that demands close tracking of children's day-to-day behavior. In the original program, therapists would at times slap children on the thigh when they did not behave as instructed, a punishment that was phased out in the late 1980's.

In 1987, Dr. Lovaas reported in a small study that 9 of 19 children who received up to 40 hours a week of his intensive therapy were classified as functioning normally after at least two years. Only 2 percent of children in a comparison group that received a less intensive version of the therapy did as well.

In a follow-up paper in 1993, Dr. Lovaas reported that those initial gains had held up through age 12 or 13 in the children, bringing a sense of hope and possibility to a field that had known mostly resignation.

Yet in 2000, a team of researchers who had trained with Dr. Lovaas tried to confirm the findings and could not. After receiving 20 to 30 hours a week of the Lovaas method for two years, only 2 of 15 children in the study reached the highest level, scoring at age level on all measures and entering regular classrooms without help, according to the study's lead author, Dr. Tristram Smith, an assistant professor of psychology at the University of Rochester. No children in the control group reached the same level, he said.

Children in the study who had full-blown autism, as opposed to a less severe disorder, did not show significant improvements as a group in most areas, compared with children who were given less intensive therapy, the study found.

Dr. Lovaas, now a professor emeritus at U.C.L.A., said in an interview that the most likely explanation for the modest findings was the quality of the therapy being delivered. "I don't know why the results were so different, but my best guess is that they did not deliver the treatment as skillfully as we do here," he said.

Yet in a review of the most recent research, accepted for publication in *The Journal of Clinical Child and Adolescent Psychology*, Dr. Sally Rogers, director of the MIND Institute at the University of California, Davis, wrote of that study: "This type of

treatment is considered by many to be the treatment of choice for lower functioning children with autism. Yet the best designed study of this treatment, carried out by experts in the method, did not demonstrate improvement in the treated group of children with the full syndrome of autism relative to controls."

In an interview, Dr. Rogers said that the Smith study by itself was too small to be conclusive, and that less rigorous trials suggested many children in intensive therapies made moderate gains in language ability and other areas, even if they did not overcome the underlying disabilities.

In one such trial, Canadian researchers found that when they taught parents how to encourage play and communication, children showed a significant gain in language skill after just three months, compared with other autistic children treated in community day care. A 2002 Norwegian study of 25 children ages 4 to 7 found that the Lovaas treatment prompted I.Q. gains of 17 points, although no child was described as recovered, according to the review. In other work, researchers who have followed children through Teacch, the Denver Model and other programs have also noted accelerated gains in I.Q. and language, among other things.

"You are talking about therapies that can raise I.Q.'s by 10 to 20 points, which is significant, and very hard to do," Dr. Rogers said.

The Fundamental Question

Still, scientists have not answered perhaps the most fundamental question about these therapies: Why does one child thrive in treatment while another, equally affected, does not?

Most researchers have hypotheses. Some believe the response could have to do with structural properties of the brain, which would show up on brain scans. Others suspect that children who do not do well in treatment have a subtle language processing problem in addition to autism.

In his long experience, Dr. Lovaas said, he has observed that children who do not learn to imitate others' speech within a few months of treatment rarely do well. And researchers in San Diego have proposed that having a basic ability to initiate social interaction is crucial to success in treatment: they found that children who tried to engage their peers frequently during a short play period did very well in therapy.

Each of these ideas is under investigation. "I expect with more research we may find that there are two groups of children - one group that does well in directed teaching, and another than needs a biomedical treatment," said Dr. Geraldine Dawson, director of the autism program at the University of Washington in Seattle. "And we would be able to tell them apart."

But teasing apart such subtle differences in language and brain structure requires careful

control, and that is one thing autism researchers do not have. With doctors emphasizing the importance of early treatment, parents of autistic children hear the clock ticking and try anything they can find. Three new surveys, of a total of 2,500 parents in North Carolina, Massachusetts and Pennsylvania, found that about three-quarters of families dealing with autism try alternative treatments, usually as an accompaniment to structured counseling programs.

One of the most popular options, tried by 50 percent to 70 percent of parents, is sensory integration, a technique in which therapists often use swings or weighted vests to help "ground" a child, and even brush children's skin with a special brush.

About 25 to 40 percent of parents, the surveys find, try special diets for their children, most often a menu free of gluten, a protein found in flour, and casein, a protein in dairy products, which some people believe prompt an allergic reaction that causes or worsens autism.

Many parents (10 percent to 30 percent) give their children large doses of vitamins like magnesium and B6 or food supplements, based on reports that these regimes have normalized behavior in some cases. And up to 10 percent of parents have paid to have their children go horseback riding, swim in a pool with dolphins or receive healing touch therapy as part of a program for autism.

Scientists say they do not have rigorously controlled evidence that any of these alternative treatments improves the core symptoms of autism: social isolation, repetitive behaviors and difficulty in developing language skills. In the surveys, parents generally agreed: individual treatments often helped with some behaviors, like agitation, but seldom altered the fundamental disability.

"There's a grief response to a diagnosis of autism; parents go through mourning and denial, and promising them their child will be cured by these therapies gives them false hope and only prolongs the grief," said Dr. Siegel, of U.C.S.F.

In fact, the surveys themselves contain hints of just how frustrated many families are: up to half the parents report that they have put their children on psychiatric medications, including antidepressants, stimulants like Ritalin and antipsychotic drugs usually prescribed for schizophrenia. These drugs can settle some of the symptoms associated with autism, like aggression, but they do not alter the underlying condition and can play havoc with some children's moods, doctors say.

In the coming years, experts say, the science of treatment should become much clearer. The National Institutes of Health is financing some 70 studies related to treatment, including a careful study of the popular gluten- and casein-free diet, being conducted by Dr. Hyman in Rochester. And a group in Wisconsin has completed a trial of Dr. Lovaas's method among 23 children, and there are 10 other sites working on similar studies, according to Dr. Lovaas and Dr. Smith, who is coordinating the research. The results from these trials, they say, look encouraging.

Still, many parents who have brought autistic children to adulthood are not holding their breath. Having tried some treatments and watched others flare out, they say change is certainly possible. But that change tends to be slow, they say, and occurs not just in their children but also in their own expectations and ways of coping.

With the help of the Teacch program, Alice Wertheimer's son David has continued through high school in special classes, learning over time to communicate, to be comfortable with himself, to have some independence. At 18, he is a young man who enjoys repeating lines from favorite movies, mimicking other students and teachers, and spending time with his parents. As a child, Ms. Wertheimer said, David rated somewhere in the middle of the autism scale, but he has come a long way. He is also still clearly autistic, although that is not how those who know him think about it.

"He is who he is," Ms. Wertheimer said, "just a great, great kid."

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