

Discovering Autism: An industry built on hope

December 19 2011, By Alan Zarembo

In 1987, Ivar Lovaas, a charismatic UCLA psychology professor, published what remains the most famous study on the treatment of autism.

Lovaas had broken down the basic skills of life into thousands of drills, such as pointing, identifying colors and reading facial expressions. For 40 hours a week on average, the therapists he trained used rewards and punishments, ranging from food treats to slaps on the thigh, to instill those abilities in 19 autistic youngsters under the age of 4.

When the study began, most of the children didn't speak and were considered mentally retarded. After a few years, nine of them tested average or above in intelligence and moved on to mainstream first-grade classrooms - a far better outcome than in two control groups.

Lovaas described the children as "recovered."

Autism, long considered a sentence of lifelong isolation, suddenly had a potential antidote. It was called "applied behavior analysis," or ABA.

As the diagnosis of autism has exploded, so has demand for ABA, the most commonly recommended treatment. It has become a thriving business, worth more than \$200 million a year in California alone.

Statewide, at least 75 firms, some with long waiting lists, offer ABA in a variety of styles. The cost - often \$50,000 a year or more for a single

child - has been covered primarily by taxpayers up to now.

In October, California passed a law requiring private health insurers to include coverage for ABA in their policies. More than two dozen other states have similar requirements, the result of relentless campaigning by parents and their [advocacy groups](#).

Yet for all the belief and investment in ABA, important questions remain about its effectiveness and how best to use it.

Researchers have established that the therapy can improve behavior, language and intelligence test scores. But no scientist using the gold standards of medical research has reproduced the success rate of Lovaas, who died last year.

Moreover, nobody can explain why some children respond to treatment and others make little progress, even after thousands of hours. It is also unclear which elements of ABA are responsible for the gains, how many hours a week are needed and for how long, and whether children who receive the therapy fare any better in adulthood than those who do not.

Complicating the picture is that scientists and providers themselves have taken the therapy in a variety of new directions. Although the principle remains the same - long hours, day after day, in early childhood - there has been little research on how various approaches compare.

Nevertheless, with few widely accepted alternatives, many parents have embraced the industry Lovaas launched. Hope of recovery is a powerful motivator for families determined to do everything they can for an autistic child. For some, "40 hours a week" has become a battle cry.

When ABA isn't working, they often demand longer and more frequent sessions. When progress has been made, they often don't want to stop.

The prospect of recovery is also a valuable marketing tool for the companies that provide ABA. One of the largest companies features success stories on its website, in a promotional documentary and at celebrity-filled fundraisers.

"We have people now in college doing extremely well," said Doreen Granpeesheh, a former graduate student of Lovaas who founded the Tarzana, Calif.-based Center for Autism and Related Disorders.

Paradoxically, ABA's popularity makes it harder to conduct studies that meet the highest scientific standards. Researchers say it can be difficult to find parents willing to have their children assigned to comparison groups, which receive less intensive treatment.

The scientific gaps make it hard to determine how best to use the limited funds available for treatment. If scientists understood which elements of ABA do what, for instance, they could better tailor the treatment to patients' needs and thereby serve more children.

As it stands, the therapy places an enormous burden on both the families who rearrange their lives around it and the school districts and state developmental system that pay for it.

Alternatives are desperately needed, said Sally Rogers, an autism treatment expert at UC Davis' MIND Institute.

"If all our interventions are based on one-to-one therapy for vast hours," she said, "very few children are going to get their needs met."

Initially, ABA was available only to families who could pay for it. But citing Lovaas' study and federal law guaranteeing educational

opportunities for disabled children, parents in the 1990s started suing - successfully - to compel California school districts to provide the therapy.

"After the first 10 hearings, we were sure we could win anywhere," recalled Granpeesheh, who testified on behalf of families.

Ill-equipped to deal with autism on their own, schools had little choice but to hire outside providers. California's Department of Developmental Services, one of the few state systems to guarantee lifelong assistance to people with debilitating autism, also began paying for ABA.

Last year, the developmental services system spent \$187 million on behavioral therapy, compared with \$5.4 million in 2001. Public schools spend tens of millions of dollars on private providers and more on their own programs, although no precise figures are available.

The therapy now takes many forms, including rigid drills conducted across a table, exercises that follow a child's lead and field trips to immerse children in the community.

Though the focus of ABA is on intensive treatment starting around age 3, many providers have expanded their services well into the school years, offering their behavior specialists as personal aides in class and on the playground.

Granpeesheh's business, which she founded in 1990, has grown to employ roughly 1,000 people, with 12 clinics in California and eight more elsewhere in the United States and abroad. In 2009, it held more than \$21 million in contracts with schools and the developmental services system in California, according to state records.

Few if any ABA companies promote "recovery" as vigorously.

Over the years, "several hundred" clients - out of many thousands treated - have progressed to the point that they no longer meet the criteria for an autism diagnosis, Granpeesheh said. They learned to speak and socialize and ceased their repetitive behaviors, she said.

She counts 8-year-old Justin Marroquin of Costa Mesa among her successes.

His mother, Laura Marroquin, had realized something was wrong shortly after he turned 1. His twin sister was starting to talk and point while he incessantly flipped light switches on and off and pushed doors open and shut.

After he was diagnosed with mild to moderate autism at 2½, the state began paying for ABA. But his language skills and behavior improved so rapidly that he was soon deemed ineligible for services.

Determined to see him progress further, his parents hired an attorney and a psychologist to pressure the school district to pay for early-intervention therapy before he entered kindergarten.

They insisted on Granpeesheh's company. Their lawyer, Bonnie Yates, had used it for her own son, now in college.

The district ultimately agreed - but wanted to scale back the hours after a year. Justin's parents fought the move and reached a legal settlement in which the district agreed to pay for ABA for two more years.

"I knew in my heart recovery was the goal," his mother said.

She will never forget June 12, 2008, the day Granpeesheh gave her the good news: Justin had beaten autism.

It had taken nearly three years of ABA and cost the Newport-Mesa School District more than \$175,000, by Laura Marroquin's estimate.

That night, she and her husband sent an email to their friends announcing that Justin's diagnosis was being removed from his medical records and that they were now "Proud parents of a 5 year old typical son."

In the subject line, they wrote "RECOVERED!!"

Such stories seem straightforward: A child is diagnosed with autism, receives ABA and gets better. But for scientists, they are difficult to interpret.

Children receive intensive treatment when their brains are already undergoing rapid change, making it difficult to sort out its effects from the gains that come with natural development. Studies that track autistic children over time show that some experience significant improvements in IQ and an easing of symptoms without any systematic treatment.

Dr. Bennett Leventhal, an autism specialist at the Nathan Kline Institute for Psychiatric Research in Orangeburg, N.Y., said that in rare cases an autistic child receiving therapy can improve enough to pass for normal.

But others who are deemed recovered "probably never really had autism in the first place," he said.

Promoting recovery amounts to "taking advantage of a vulnerable population," Leventhal said.

"These are families who are desperate. Their children are disabled.

They'll do anything for them to make them well."

Lovaas didn't set out to cure autism.

He was interested in the emerging science of behavior modification, and a new approach that University of Kansas researchers called "applied behavior analysis" caught his attention. He wanted to put it to the test and saw autistic children as the ultimate challenge.

For all the excitement his 1987 study generated, it quickly came under fire.

The main criticism was that he did not assign children to treatment and control groups on a random basis - raising the possibility that the results were skewed by his selections.

Eager to silence his skeptics, Lovaas went on to make treatment of autism his life's work. As his methods evolved over the years, he stopped using physical punishment.

Hundreds of studies of ABA have generated a body of evidence showing that it can help some autistic children. The American Academy of Pediatrics said in 2007 that children who receive it "have been shown to make substantial, sustained gains."

But multiple reviews of the scientific literature have raised questions about the quality of ABA research. Most studies have relied on small numbers of children, have not tracked subjects over the long term and - like Lovaas' original study - have failed to use comparison groups selected at random.

One extensive review, conducted for the federal government by experts at Vanderbilt this year, judged most studies of the intensive intervention

for autism to be "fair" or "poor" in quality and expressed "low" confidence in some of the improvements attributed to the treatment.

The Vanderbilt researchers, like other autism experts, called for more-rigorous studies so ABA's benefits and limitations can be better understood.

The ultimate validation of Lovaas' work - a randomized clinical trial under carefully controlled conditions - has proved elusive.

One of the only attempts was conducted by Tristram Smith, a former Lovaas graduate student who is now a professor of pediatrics at the University of Rochester. It took him five years to find enough families willing to enlist their children in the study.

The results, published in 2000, cast doubt on Lovaas' conclusions. Children with full-fledged autism - like those in the Lovaas study - showed minimal improvement. The benefits of treatment were mostly limited to youngsters with a milder form of the disorder.

The findings challenged the prevailing view that resources should be concentrated on the gravest cases. Smith believes every autistic child deserves a chance at ABA, but says those who don't respond quickly - developing speech within six months and showing big improvements in IQ or basic life skills within a year - should be given less rigorous, and less expensive, services instead.

"There should be periodic evaluation to see whether the kids are really catching up to other kids," Smith said.

He said the window for major benefits from early intensive therapy appears to close around age 7.

Morgan Ransdell started intensive ABA around the time she turned 4. Today, at 14, she still receives 10 hours of therapy per week at her home, in the Sacramento suburb of Granite Bay.

All through her school years, a behavioral aide from an ABA company has accompanied her throughout the day to keep her on track in a mainstream classroom.

When the Eureka Union School District tried to close a budget shortfall by eliminating contracts with ABA providers, her mother, Rhonda, fought successfully to hang on to Morgan's services.

Ransdell believes ABA with the therapists she knows and trusts is still Morgan's best chance to live independently some day, hold a job or fall in love.

"She's going to function at a high level," her mother said. "But you can't put a date on it."

Such faith in ABA has led others to disappointment.

"I used to be one of the believers," said Ryan Reformina, an operating room nurse who lives in Glendale. He has seen the children of friends make great strides. When his own son began therapy more than two years ago, he dared to imagine the possibility of recovery.

"Your hopes are up," he said. "Your adrenaline is up."

Today, he said, 5-year-old Sam has acquired some basic skills but in other ways seems "more profoundly autistic to me now than he was before."

Although they are continuing the therapy, Reformina and his wife have lowered their expectations. At times, they wonder whether the gains will be worth the time and emotion they've invested.

"We're just tired," Reformina said.

Rick Rollens, a Sacramento lobbyist, represents ABA providers and was instrumental in bringing policymakers' attention to [autism](#) in the 1990s.

Rollens is convinced the therapy helped his severely autistic son. But he has come to understand its limitations.

Russell started ABA at 27 months and continued it for more than six years. "I had Ivar Lovaas himself running our program," his father said.

Today, at 21, Russell barely speaks, bites his hand when he becomes frustrated and can't be trusted to cross the street by himself. He is unlikely ever to achieve independence - a reality that Rollens said he has reluctantly accepted.

"If my son just had the ability to talk, we would consider that recovery," he said. "The heck with the rest."

More information: *ABOUT THIS SERIES: Rates of autism have exploded over the last 20 years. In exploring the phenomenon and its repercussions, Los Angeles Times staff writer Alan Zarembo interviewed dozens of clinicians, researchers, parents and educators and reviewed scores of scientific studies. Zarembo, along with Doug Smith and Sandra Poindexter of the Times data team, also analyzed autism rates and public spending on autism in California.*

(c)2011 the Los Angeles Times

Distributed by MCT Information Services

Citation: Discovering Autism: An industry built on hope (2011, December 19) retrieved 19 April 2024 from <https://medicalxpress.com/news/2011-12-autism-industry-built.html>

This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.