

Discovering Autism: An unsettling boom

19 December 2011, By Alan Zarembo

Amber Dias couldn't be sure what was wrong with her little boy.

Chase was a bright, loving 2 1/2-year-old. But he didn't talk much and rarely responded to his own name. He hated crowds and had a strange fascination with the underside of the family tractor.

Searching the Internet, Dias found stories about other children like Chase - on websites devoted to autism.

"He wasn't the kid rocking in the corner, but it was just enough to scare me," recalled Dias, who lives with her husband and three children on a dairy farm in the town of Kingsburg in California's Central Valley.

She took Chase to a psychologist in Los Angeles, who said the boy indeed had autism and urged the family to seek immediate treatment.

But a team at the Fresno agency that arranges state-funded services for autism said Chase didn't have the disorder. His problems, staff members said, were nothing more than common [developmental delays](#) that he would eventually outgrow.

Unconvinced, Dias imagined the worst - that Chase would never have a girlfriend, a job, a place of his own. She pressed the agency to reconsider and hinted at a lawsuit. Finally, officials relented, and her son began receiving 40 hours a week of [behavioral therapy](#) with a private tutor.

A generation ago, society most likely would not have intervened in the life of a boy like Chase. Today, milder cases such as his are helping to fuel an explosion in the diagnosis and treatment of autism.

The U.S. [Centers for Disease Control and Prevention](#) estimates that nearly 1 percent of children across the country have some form of autism - 20 times the prevailing figure in the 1980s.

The increase has stirred fears of an epidemic and mobilized researchers to figure out what causes the brain disorder and why it appears to be affecting so many more children.

Two decades into the boom, however, the balance of evidence suggests that it is more a surge in diagnosis than in disease.

Factors that have nothing to do with biology can explain much of the steep increase in cases around the world: an expanded definition of autism, spreading awareness of the disorder and an improved ability to distinguish it from other conditions.

The search for an environmental explanation for the rise in cases has so far been fruitless.

Roy Richard Grinker, an anthropologist at George Washington University who has studied autism around the globe, said that what some call an epidemic is really an "[epidemic](#) of discovery."

"Once we are primed to see something, we see it and wonder how we could have never seen it before," he said.

Dr. Allen Frances, former chairman of psychiatry at the Duke University School of Medicine, said the widespread alarm over autism rates "makes no sense."

"People don't change that fast," he said. "Labels do."

Many parents of autistic children insist the upsurge is too large to be an illusion, and experts do not rule out the possibility that some real increase has occurred. But if so, many scientists say, it can account for only a modest part of the growth in diagnosis.

Nevertheless, society is marshaling resources in the name of autism as never before. In California alone, the cost of state-funded developmental

services for people with autism has climbed more than 300 percent over the last decade, to \$638 million annually.

In California public schools, the number of students receiving autism services has grown fivefold since 2000, driving up special education costs even as school budgets are being slashed.

Most experts see wider diagnosis - and increased spending - as progress. Children who in the past would have been overlooked, misunderstood or deemed hopeless cases are receiving help. But some of the same experts say that in the sweeping effort to find autism, some children are being mislabeled.

Diagnosis rates - and therefore spending on treatment - vary dramatically from place to place.

In California overall, 1.1 percent of public elementary school students have been identified as autistic, a Los Angeles Times analysis found. But the rate in Orange County (1.6 percent) is nearly triple that of Fresno County. Many rural school districts list no autistic students at all.

Autism accounts for 14 percent of the caseload at the Central Valley Regional Center, one of the nonprofit agencies that arrange state-funded services for people with developmental disabilities. At the seven regional centers in L.A. County, it accounts for 34 percent.

Such variations are seen across the country. The autism rate in Minnesota schools, for example, is 10 times that in Iowa.

Researchers say the differences are too wide to represent true disparities in the prevalence of autism. More likely, they are the signature of social and cultural forces, reflecting how new perceptions and attitudes about autism have taken root to different degrees in different places.

Southern California, long a center of autism research and treatment, is simply further along.

But nearly everywhere, the new iteration of autism is spreading, one child at a time.

A driving factor is that parents, physicians and educators have become intent on identifying it as early as age 2, in the hopes of diminishing its symptoms through treatments that are now widely available.

"It used to be that autism was the diagnosis of last resort," said Catherine Lord, director of the Institute for Brain Development at New York-Presbyterian Hospital and a leading authority on autism diagnosis. "Nobody wanted it. Now it is seen as preferential."

Indeed, some parents pursue it doggedly - even in court - because it can open the door to publicly funded services.

As Amber Dias pondered what to do about Chase, she recalled the social outcasts from her own school days.

"I didn't want him to be the weird kid that everybody pointed at," she said.

Dias, 30, believes that two years of intensive therapy, along with her family's faith in God, saved her son from a lifetime of isolation. Now 8, he blends in easily among his classmates.

"He has tons of friends," Dias said. "We don't have any issues anymore."

As for his previous behavior, she said she's not sure if it was "pure autism" or not.

"But I didn't take a chance."

Nobody knows what causes autism, and there is no blood test or other biological marker.

It is diagnosed by its symptoms. In sufficient numbers and specific combinations, traits such as lack of empathy, difficulty communicating and strict adherence to routines - as well as self-mutilation and other severe behaviors - add up to a diagnosis.

Ultimately, it comes down to clinical judgment.

First described in 1943 by Dr. Leo Kanner, a psychiatrist at Johns Hopkins University, autism was long seen as a condition so dire that most parents had no choice but to place their afflicted children in institutions.

A leading expert once described them as "little monsters" who would bite their fingers off, smear feces on the wall and show no signs of warmth toward others.

"You have a person in a physical sense - they have hair, a nose and a mouth - but they are not people in the psychological sense," the late Ivar Lovaas, a UCLA researcher, said in a 1974 interview with *Psychology Today*.

The view of autism as invariably severe and lifelong still prevailed in 1980, when it was first listed in the *Diagnostic and Statistical Manual of Mental Disorders*, the bible of U.S. psychiatry.

Today, autism comes in many manifestations, collectively known as "autism spectrum disorder," and encompasses a huge range of children - mostly boys - from the mute child who bangs his head on the wall to the preternaturally bright youngster who can't stop talking about the intricacies of the subway.

Growth is occurring at both ends of the spectrum.

On the severe end are children who in the past might have been considered mentally retarded, schizophrenic or even psychotic.

The California Department of Developmental Services, which focuses on the more debilitating cases, set off a national alarm in 1999 when it reported 12,000 cases, a 200 percent rise in a decade.

The number has since increased more than fourfold and now exceeds 55,000. Because most patients remain in the system for life, the count is likely to continue to rise for decades.

California's public schools serve students from across the spectrum, including many with milder symptoms. Since schools started tracking autism in

1991, the caseload has climbed precipitously - to nearly 14,000 by 2000 and nearly 70,000 by 2010.

Growth in milder cases accelerated after the 1994 edition of the psychiatric manual added a new diagnosis to the spectrum: Asperger's disorder, for children with autistic behaviors but no speech problems or intellectual deficits.

Duke University's Frances, leader of the scientific panel that created that edition, said the change unintentionally opened a floodgate.

"People started seeing it whenever a kid does something the slightest bit strange or starts collecting too many baseball cards," he said.

The definition is set to change again when the next edition of the manual is published in 2013, with the aim of greater consistency in diagnosis.

Still, the guiding principle for clinicians will remain that "it's more of a tragedy when somebody gets missed than when somebody on the border gets misdiagnosed," said Lord, of New York-Presbyterian.

The extent of autism's transformation became apparent in a massive survey of parents published in 2009. U.S. health authorities were surprised to find that nearly 40 percent of children once identified as autistic no longer had the diagnosis. The findings suggest that autism, still officially a lifelong condition, has become such a broad and fluid concept that it can be temporary.

Researchers looking for environmental causes of the autism boom keep stumbling across other explanations.

Irva Hertz-Picciotto, an epidemiologist at the University of California, Davis, suspects that environmental triggers such as exposure to chemicals during pregnancy play a role. In a 2009 study, she started with a tantalizing lead - several autism clusters, mostly in Southern California, that her team had identified from disability and birth records.

But the hot spots could not be linked to chemical plants, waste dumps or any other obvious environmental hazards. Instead, the cases were concentrated in places where parents were highly educated and had easy access to treatment.

Peter Bearman, a sociologist at Columbia University, has demonstrated how such social forces are driving autism rates.

Analyzing state data, he identified a 386-square-mile area centered in West Hollywood that consistently produced three times as many autism cases as would be expected from birth rates.

Affluence helped set the area apart. But delving deeper, Bearman detected a more surprising pattern that existed across the state: Rich or poor, children living near somebody with autism were more likely to have the diagnosis themselves.

Living within 250 meters boosted the chances by 42 percent, compared to living between 500 and 1,000 meters away.

The reason, his analysis suggested, was simple: People talk.

They talk about how to recognize autism, which doctors to see, how to navigate the bureaucracies to secure services. They talk more if they live next door or visit the same parks, or if their children go to the same preschool.

The influence of neighbors alone accounts for 16 percent of the growth of autism cases in the state developmental system between 2000 and 2005, Bearman estimated.

In other words, autism is not contagious, but the diagnosis is.

"Is it real or not?' is a meaningless question," Bearman said of the surge in cases. "The sociological processes are as real as the biological processes."

Of all the advice Laurie Bailey received when she

began to see signs of autism in her son, one piece proved most valuable.

"If you embrace that word" - autism - "you will get far more services," a friend told her.

Three-year-old Benjamin was nothing like the severely impaired children Bailey had seen in clinic waiting rooms. But he didn't speak much, was mesmerized by ceiling fans and liked to be left alone.

On the day of his evaluation by specialists from the L.A. Unified School District, Bailey purposely didn't feed him breakfast. "I wanted him to look as bad as possible," she recalled. "It's not like he didn't deserve services. I just wanted to stack the odds in our favor."

It worked. Benjamin threw a tantrum. Over the next three years, the district paid for speech therapy, motor skills training and the attention of a one-on-one aide throughout the school day.

Benjamin's behavioral problems faded, though some learning difficulties remain. In 2009, his mother took him to a specialist to end her confusion over whether he was - or had ever been - autistic.

The doctor told her the answer was unclear - but volunteered to provide a written diagnosis of autism if it would help Benjamin get treatment, Bailey recalled. She declined the offer.

In ambiguous cases, some clinicians see it as their moral duty to diagnose autism.

Dr. Nancy Niparko, a child neurologist in Beverly Hills, said that whether she identifies a child as autistic can come down to whether she believes it will do any good.

"If it's going to improve the possibility of getting services that will be helpful, I will give the label," she said.

"I don't work for labels. Labels work for me."

For Rima Regas, the search for the right label spanned several years and several states.

Her 13-year-old daughter, Leah, comes across as evidence for autism is weak. highly articulate and intelligent, slightly robotic in her interactions and very dependent on her mother, who home-schooled her from second grade until enrolling her in community college this year.

As her father changed jobs and the family moved, Leah accumulated diagnoses, including a speech delay, attention deficit hyperactivity disorder, sensory issues and Asperger's disorder.

Her mother, however, came to believe that Leah had full-fledged "autistic disorder," the most severe diagnosis on the spectrum and a prerequisite for state developmental services.

"We wanted a diagnosis of autism," Regas said. "We knew she needed help."

She eventually found two [psychologists](#) who diagnosed autistic disorder. Experts at the Westside Regional Center in Culver City, however, challenged that conclusion. The case went before a state administrative law judge, who ruled that Leah had Asperger's disorder, a form of autism too mild to qualify for state services.

Two years later, the regional center serving Orange County, where the family now lives, reviewed Leah's records and concluded that she had autistic disorder after all.

Throughout her quest for help, Regas found allies online. "I'd learn from the other parents - how they got their kids diagnosed, who they saw," she said.

Bryna Siegel, who heads the autism clinic at the Langley Porter Psychiatric Institute at UC San Francisco, believes the radical shift in autism diagnosis has swept up some children who don't have the disorder.

Mislabeling children can damage them psychologically and lead to wasteful spending, she said.

As a frequent consultant on contested cases, she often critiques evaluations and finds that the

To illustrate her point, Siegel shared with the Los Angeles Times the records of a 7-year-old girl, after redacting her name and other identifying information. Siegel had been hired by one of the state's regional centers to review the girl's autism diagnosis.

According to the girl's mother, she threw tantrums, had difficulty making friends and asked inappropriate questions, the records said. In addition, she avoided sidewalk cracks and collected hair and cigarette butts.

The clinicians who had diagnosed the girl with autism observed that she had trouble making small talk or steady eye contact and using her imagination.

She had performed outside the autism spectrum on a key test of social and communication skills, but the evaluators discounted the score, saying: "We feel this belies her social deficits."

Siegel also noted that testers had at various points written that she was "friendly and cheerful," engaged easily in conversation and used a variety of gestures and facial expressions.

"The girl told me about her friends," said Siegel, who interviewed her and her mother during a two-hour video conference.

Siegel suspected that the girl's problems stemmed from obsessive compulsive disorder and poor discipline at home. She worried that an autism diagnosis could forever change the way the girl viewed herself and the expectations others had of her.

In any case, she said, there were plenty of other children in greater need. "Resources are not infinite," Siegel said.

She felt certain she was right. No doubt, so did the experts who made the diagnosis. They were from the Autism Evaluation Clinic at UCLA, one of the world's leading centers of autism research.

The clinic assesses children mainly for research purposes, but it also evaluates about 100 children a year to advise parents on treatment or offer second opinions. In those cases, it charges more than \$4,000 for an assessment that can carry great weight with schools, the state developmental system and judges.

UCLA officials said they could not discuss individual clients. But in general, said clinic director Pegeen Cronin, her team frequently identifies overlooked cases of autism by using the newest and most reliable diagnostic tools and spending more time with the children.

Often, they uncover autism in those who do well in school but have serious trouble relating to others, Cronin said.

"Nobody's peeled back the layers to say, 'Yeah, you have a smart kid, but there are these social issues,' " she said.

Research suggests that there are many more such cases waiting to be discovered.

Before a team of U.S. and South Korean researchers used questionnaires and extensive evaluations to look for autism in a suburb of Seoul, South Korean health officials considered the disorder to be extremely rare in that country.

But the team, in results published this year, estimated that 2.64 percent of the 55,000 children in the town had some form of the disorder - the highest rate ever found in a general population. The researchers said they believed autism was no more prevalent there than anywhere else; they had simply looked more thoroughly.

Two-thirds of the children they identified had never previously been diagnosed with autism or any other disability.

One morning in Huntington Beach, five preschool boys played dodgeball on a patch of grass, each with a school aide at his side, offering a stream of instructions and praise:

"Pay attention!"

"Nice throw!"

"Give him a high five."

To the untrained eye, many seemed like ordinary kids. Yet all were considered autistic to some degree, and all qualified for an early intervention preschool in the Ocean View Elementary School District in Orange County.

The district has one the highest rates of autistic children in the state: 3 percent of the 6,400 elementary students - including more than 6 percent of white boys - according to a Times analysis of 2010 data.

After costly lawsuits from parents in the late 1990s, the district began aggressively identifying and treating children starting at age 3, when the law requires schools to take responsibility for those with special needs. The caseload has quadrupled over the last five years. The vast majority are deemed "high-functioning."

Nearly 200 miles north, in the Central Valley town of Mendota, six of 1,316 elementary students in the school district were considered autistic last year. That's less than half of 1 percent.

Rodney Smith, a psychologist in charge of special education, said he did not believe the district was under-identifying autism.

"That you can't miss - a real case of autism," he said. "If you have a severe child, really autistic - we're not talking mild - they won't manage in a regular classroom."

Some parents in the Central Valley, though, say the diagnosis is too elusive in their part of California, putting treatment out of reach for their youngsters.

In the farm town of Sanger, Pam Bezemer helped form a support group for parents of special education students after struggling to persuade the school district that her son was autistic.

Ean, now 10, has a history of behavior problems and social difficulties and a fixation on military history and equipment. The school district eventually agreed he has autism, though his primary designation for special education remains "emotionally disturbed."

Maria Gutierrez, another parent in the group, has come to believe the local experts were wrong about her boy as well.

Joseph, 13, is practically mute. He paces the backyard and obsessively presses the garage door opener. He bites and pinches and shoves when he gets frustrated.

For years, his mother believed he was mentally retarded and nothing more. Then a cousin who heard a celebrity activist talk about autism on TV suggested that Joseph might have the disorder.

Gutierrez, who works in a factory packaging raisins, had never heard of autism. Now she badly wants a diagnosis for her son.

A school psychologist told her Joseph couldn't have the disorder because he likes being around people. The Central Valley Regional Center said he was not autistic. One local specialist said he couldn't rule out [autism](#); another couldn't say one way or the other.

If only she had the money, his mother said, she'd take him to Los Angeles to be diagnosed.

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.*

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