

Discovering Autism

Autism boom: an epidemic of disease or of discovery?

Autism rates have increased twentyfold in a generation, stirring parents' deepest fears and prompting a search for answers. But what if the upsurge is not what it appears to be?

Alan Zarembo, Los Angeles Times
December 11, 2011

First of four parts

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, Amber 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 Central Valley town of Kingsburg.

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 one-on-one behavioral therapy.

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 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."

Discovering Autism

Why autism? There is no single answer

Theories abound on the genetic and environmental links to autism, but scientists have all but given up on finding one thing to explain it. The disorder's causes are almost certainly numerous and complex.

Alan Zarembo, Los Angeles Times
December 11, 2011

Asking what causes autism is a little like asking what causes cancer. Scientists have all but given up on finding one gene, virus or chemical that can explain it. The causes are almost certainly numerous and complex. "If there was one single thing, we would have found it by now," said Lisa Croen, a Kaiser Permanente epidemiologist who studies possible environmental causes of the brain disorder. Researchers have been more successful in ruling out popular theories – notably that autism is engendered by "refrigerator mothers" who failed to connect emotionally with their children or, more recently, that it results from vaccinations. Studies of twins starting in the late 1970s established that autism has a strong genetic basis. If one twin has autism, researchers have found, the chances that the other does too depend largely on how much DNA they share. The odds are far higher – up to 90 percent – if the twins are identical. Scientists have identified a few dozen gene variations more common in people with autism. Still, the genetic mechanisms of the disorder remain poorly understood. None of the variations identified thus far has been found in more than 1 percent of autism cases; none guarantees that a child will have autism; and roughly 80 percent of cases can't be linked to any of them.

In coming years, scientists expect to discover many more genes linked to autism, possibly hundreds. But they probably are not the sole culprit. As in many medical conditions, the most likely scenario is that genes create a susceptibility, while environmental factors – which scientists broadly define to include such things as diet, drug use, radiation exposure and stress levels – act as triggers. So far, the search for triggers has yielded little more than hypotheses. Scientists say it's most likely that something damages a fetus in the first few months of development, when billions of neurons are being connected to form the hardware of the brain. Some research suggests that the risk of autism rises with fetal exposure to the rubella virus and to two drugs – valproic acid, a mood stabilizer, and misoprostol, an ulcer medication sometimes used in illicit abortions. But that can't account for many cases because the exposures are extremely rare. The link to misoprostol emerged from a study of autistic children in Brazil who survived abortion attempts using the drug. The studies raise the possibility that other compounds, viruses or bacteria could have an effect. "We know children are being exposed to a number of chemicals that didn't exist two decades ago," said Dr. Philip Landrigan, a pediatrician and epidemiologist at Mount Sinai School of Medicine in New York.

Some studies provide tantalizing associations but don't point to clear causes. Mothers of children with autism are more likely to have taken antidepressants known as selective serotonin reuptake inhibitors during pregnancy – and less likely to have taken prenatal vitamins – than the mothers of other children. Autism rates are higher in children living near freeways. In California, children conceived in the winter have a slightly higher risk of being diagnosed with autism than ones conceived in July. The risk of autism is also higher in children of older parents. No study points to an environmental reason for the worldwide explosion in cases over the last two decades. Given the slow pace of genetic change in large populations, genes can't account for the surge either. That suggests the explanation for the boom lies mainly in social and cultural forces, notably a broader concept of autism and greater vigilance in looking for it.

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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, including speech, behavioral and other therapies, 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."

No more 'monsters'

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 rise of more than 200 percent 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.

Looking for a reason

Researchers looking for environmental causes of the autism boom keep stumbling across other explanations. Irva Hertz-Picciotto, an epidemiologist at UC 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."

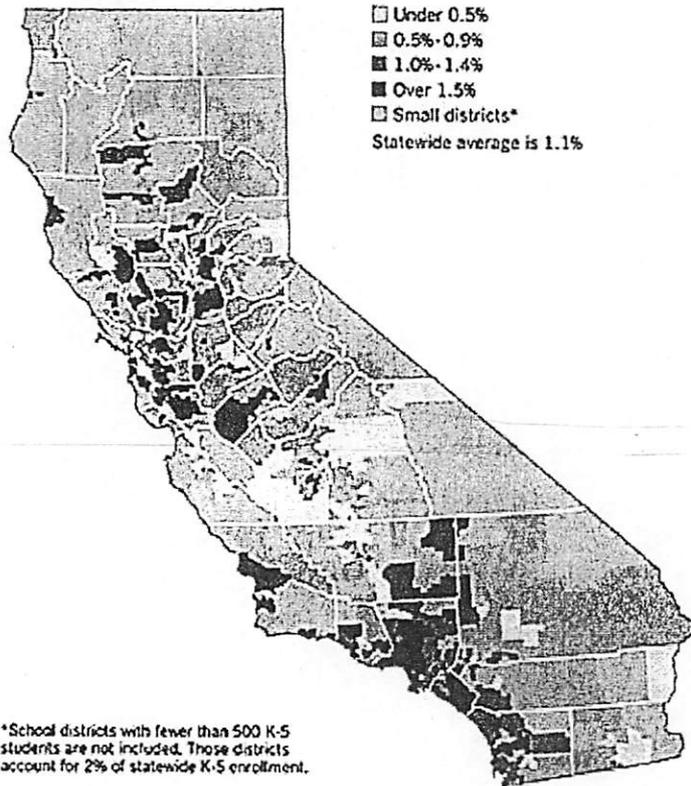
Securing services

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.

Disparities in Diagnosis

Rates of autism in California school districts vary widely, reflecting how a broader conception of the disorder has taken hold unevenly. Data below are for kindergarten through the 5th grade.

Autism rate by school district in 2010



Source: Los Angeles Times analysis of California Department of Education data.

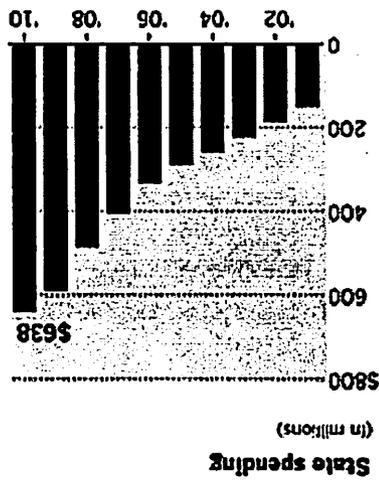
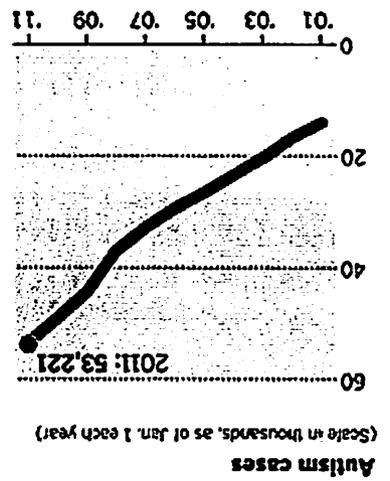
Graphics reporting by Alan Zarembo. Data analysis by Sandra Poindexter

Thomas Suh Lauder, Doug Stevens Los Angeles Times

Rising caseloads, rising costs

Autism accounts for a rising share of the caseload in California's developmental services system.

That has driven up spending on autism services



Source: California Dept. of Developmental Services. Graphics reporting by Alan Zarembo

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 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.

Weak evidence

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 evidence for autism is weak. To illustrate her point, Siegel shared with The 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.

Early intervention

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 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.

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About the 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.

The series at a glance:

Part 1: An epidemic of disease or of discovery?

Part 2: Services go to those who fight hardest.

Part 3: Families chase the dream of recovery.

Part 4: Finding traces of autism in earlier eras.

Discovering Autism

Warrior parents fare best in securing autism services

Public spending on children with autism in California varies greatly by race and class. A major reason: Not all families have the means to battle for coveted assistance.

Alan Zarembo, Los Angeles Times
December 13, 2011

Second of four parts

From the day her son was diagnosed with autism nine years ago, Stacie Funk has made it her full-time job to find him the best possible help. Hiring lawyers and experts to press her case, she established herself as a mother whose demands could not easily be dismissed. The result has been a bounty of assistance for Jonah: A behavioral therapist who works with him at home and comes along on family outings, a personal aide at school and specialists to design his curriculum, improve his speech and refine his motor skills. So far, the state of California and the Los Angeles Unified School District have spent at least \$300,000 on specialized services for Jonah. Now 13, he bites his hands, pinches his younger siblings and is easily flustered by changes in routine. But his mother is proud of the progress he's made – his ability to express his needs, read aloud and surf the Internet for movie trivia. The outside support, she said, helps hold the family together. "Am I more entitled than someone else?" said Funk, of Encino, whose husband owns a trophy-parts business. "No. But that's how the system is set up."

Getting a wide array of help for an autistic child can require waging a small war with the gatekeepers of state and school district services. But not all parents have the time and resources to fight the way Funk did. That contributes to striking disparities in how services are distributed. Public spending on autistic children in California varies significantly by racial or ethnic group and socioeconomic status, according to data analyzed by the Los Angeles Times. For autistic children 3 to 6 – a critical period for treating the disorder – the state Department of Developmental Services last year spent an average of \$11,723 per child on whites, compared with \$11,063 on Asians, \$7,634 on Latinos and \$6,593 on blacks. Data from public schools, though limited, shows that whites are more likely to receive basic services such as occupational therapy to help with coordination and motor skills. The divide is even starker when it comes to the most coveted service – a behavioral aide from a private company to accompany a child throughout each school day, at a cost that often reaches \$60,000 a year. In the state's largest school district, Los Angeles Unified, white elementary school students on the city's affluent Westside have such aides at more than 10 times the rate of Latinos on the Eastside.

It might be tempting to blame such disparities on prejudice, but the explanation is more complicated. "Part of what you're seeing here is the more educated and sophisticated you are, the louder you scream and the more you ask for," said Soryl Markowitz, an autism specialist at the Westside Regional Center, which arranges state-funded services in West Los Angeles for people with developmental disabilities. In both the developmental system and the schools, the process for determining what services a disabled child receives is in essence a negotiation with the parents. Because autism has come to encompass such a broad range of children – from those who

never learn to speak or use a toilet to math whizzes unable to make friends – there is often bitter disagreement over what a child needs and who should pay. The financial squeeze on school and state budgets has turned up the temperature, leaving officials caught between legal mandates to help autistic children and pressure to curb spending. In California last year, autism accounted for one tenth of special education enrollment but one third of the disputes between schools and parents on record with the state.

Carmen Carley, a professional advocate for families seeking public services, said parents who present themselves as formidable opponents fare best. "Wear a fake diamond ring," she tells mothers who don't have a real one. "Make them think you're ready to fight. Don't show them you're weak. Don't show them you're tired." Carley, of Torrance, gained her expertise by advocating for her own son, Collin, now 14. He received state-funded behavioral therapy for more than eight years as a result of her efforts, which included taking the officials at the Harbor Regional Center in Torrance before a judge.

In contrast to warrior parents, some families simply accept what they are offered. Gissell Garcia of South Los Angeles was diagnosed with autism at age 3, early enough that intensive therapies might have helped. But her parents, Mexican immigrants who support themselves on the father's factory job, say that neither L.A. Unified nor state officials ever mentioned the possibility. The couple requested a one-on-one aide for Gissell. She had a habit of inserting objects into her ears and nose, and they worried she might hurt herself. But school officials said there were enough staff members in her special education classroom to keep an eye on her. For several years, Gissell has received speech therapy for 30 minutes a week during school. "I didn't ask for anything more," her mother, Yolanda Ortega, said in Spanish. "I accepted it because I didn't know. I thought she would eventually talk." Now 11, Gissell has learned to point when she wants something. The sounds she makes are unintelligible.

The Lanterman Act

In the 1960s, a group of mothers from Marin County campaigned for state legislation to help them raise their mentally retarded children at home. The result, the Lanterman Act, ended the long-standing practice of warehousing people with developmental disabilities in state hospitals and provided state-funded services tailored to individual needs. Few other states have anything like it. Services are free for life, regardless of a family's means. Last year the system cost taxpayers about \$4 billion, including \$638 million for services for autistic clients.

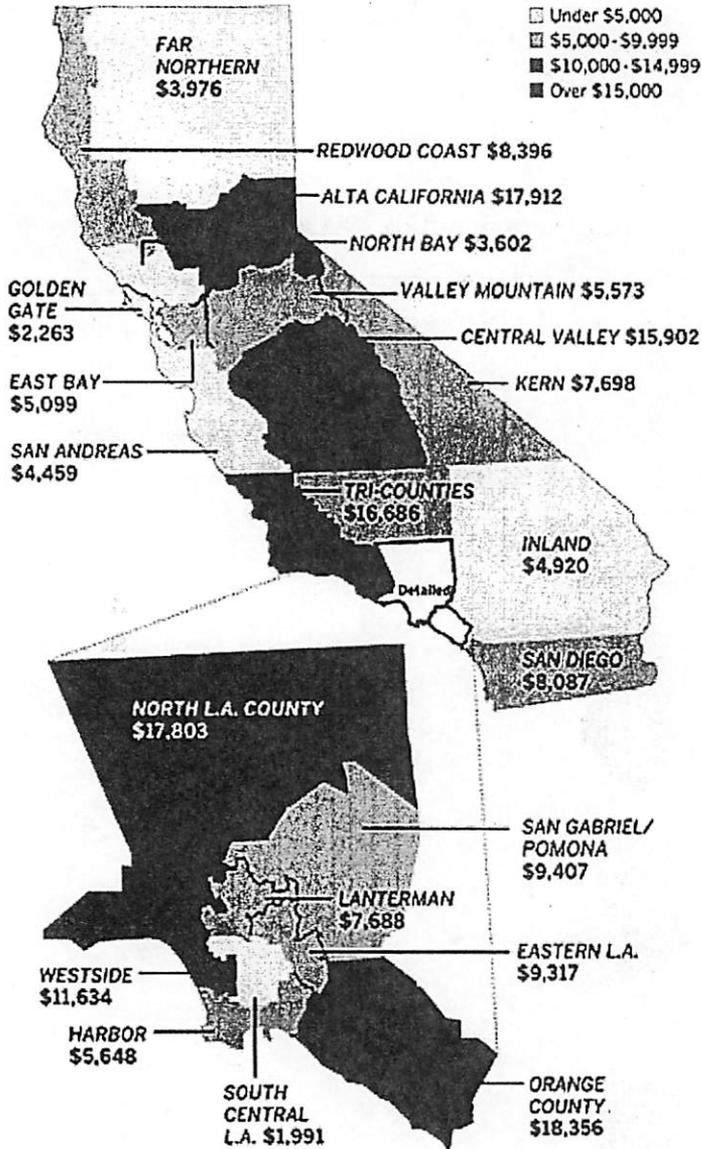
The money flows from the state Department of Developmental Services to service providers through 21 regional centers, nonprofit agencies that function as case managers. They determine whether a child has a qualifying disability and what help to provide. Though all regional centers are supposed to follow the same criteria, average spending per child varies widely from place to place and race to race, according to data obtained by The Times under the California Public Records Act. Last year, the system served 16,367 autistic children between the critical ages of 3 and 6, spending an average of \$9,751 per case statewide. But spending ranged from an average of \$1,991 per child at the regional center in South Los Angeles to \$18,356 at the one in Orange County. At 14 of the 21 centers, average spending on white children exceeded that for both blacks and Latinos.

Uneven spending

State-funded autism services are supposed to be awarded based on each child's needs.

But a Times analysis found that average spending per child varies widely among the state's 21 regional centers for developmental services.

Average spending per autistic child age 3 to 6, by regional center

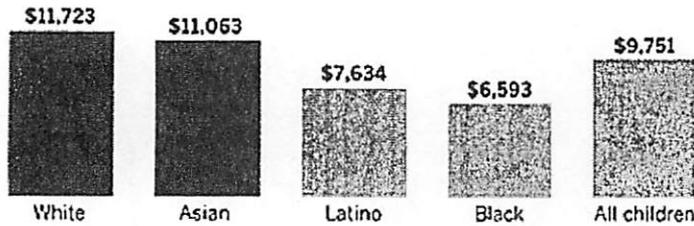


Source: California Dept. of Developmental Services. Graphics reporting by Alan Zarembo
Data analysis by Sandra Poindexter

Thomas Suh Lauder, Doug Stevens Los Angeles Times

Racial disparities

The level of autism services also varies by race and ethnicity. Here are figures on average spending per autistic child across the developmental services system.



Source: California Dept. of Developmental Services. Graphics reporting by Alan Zarembo
Data analysis by Sandra Poindexter

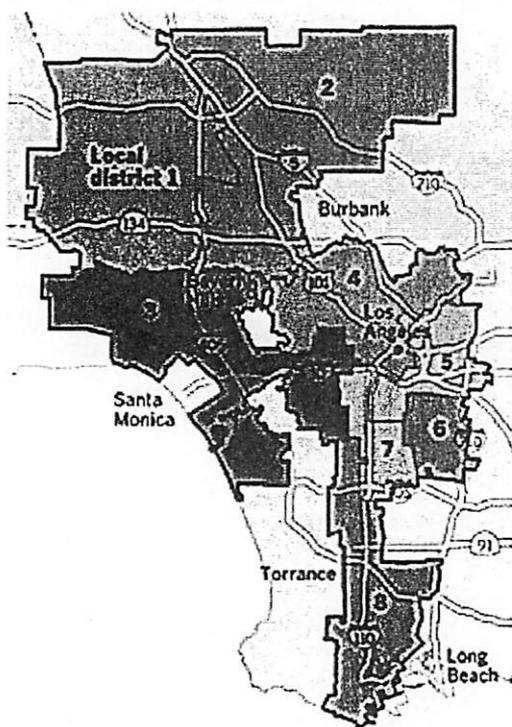
Thomas Suh Lauder, Doug Stevens Los Angeles Times

Individual attention

Like other school districts, L.A. Unified pays for one-on-one personal aides for some autistic children. White students in affluent areas are more likely to have them.

Autistic children ages 5 to 11 with privately contracted aides

Less than 10%
 10-20%
 More than 20%



Districtwide, by race



Source: Los Angeles Unified School District. Graphics reporting by Alan Zarembo
Data analysis by Doug Smith and Sandra Poindexter
Los Angeles Times

Through a spokeswoman, officials at the Department of Developmental Services declined to discuss the disparities. In written statements responding to questions, they said the department has long been aware of such differences and attributed them to language and cultural barriers, as well as to shortages of service providers in certain areas. Marsha Mitchell-Bray, director of community services at the South Central Los Angeles Regional Center, which serves mostly Latinos and blacks, said these families often feel stigmatized by an autism diagnosis and take only minimal advantage of the services available. "Even though they have the diagnosis, they still aren't coming to terms with it," she said.

At the Frank D. Lanterman Regional Center, which serves a swath of Los Angeles County stretching from Hollywood to Pasadena, spending on white youngsters with autism averaged \$12,794 per child last year – compared with \$9,449 for Asians, \$5,094 for blacks and \$4,652 for Latinos. Diane Anand, the executive director, said many minority children enrolled in the system receive few or no services because their parents can't participate as required in orientations or therapy sessions. Anand faulted state officials for failing to research the causes of the disparities. "I don't know what you do about some of this," she said. "This is an issue that has bedeviled our service system for years and years."

A personal aide

Of all the school services available for autism, few are as desirable as a behavioral aide – a full-time assistant to shadow a child from class to class, help with assignments, curtail troublesome conduct and foster good relations with peers.

Samantha Staszower of Westchester had such an aide in kindergarten, provided by L.A. Unified through a private company. But as she prepared to enter first grade last year, school officials informed the family that she was no longer eligible and that district staff could keep her focused and well-behaved. "They're messing with the wrong set of parents," said her father, Steve Staszower. A lawyer himself, he looked for a special education attorney and began selling off his treasured comic book art collection "to build a war chest." On the autism spectrum, Samantha was deemed high-functioning – talkative, affectionate and too bright for special education – but far below average socially. She struggled to sit still and relate to other children, and she spoke of little but reptiles. "I won't throw her to the wolves," said her mother, Tracy Jacobson, an elementary school teacher in another district who is divorced from Samantha's father. By fall 2010, the family was preparing to take the matter before one of the state's administrative law judges. Then the district backed down. Samantha, now 8, is in second grade with a personal aide firmly in place.

As more autistic children are moved into regular classrooms, more parents are demanding such assistants to keep their children engaged and well-behaved. L.A. Unified expects to spend more than \$50 million this school year to provide 1,182 autistic students with aides from private companies. Those students represent 11 percent of the district's autism cases. District statistics suggest need is not the only factor in determining who receives the service. In elementary schools, where private aides are most common, 31 percent of white students with autism have one this school year – roughly twice the rate for Asians and blacks and 3 1/2 times that for Latinos. Reliance on such aides varies dramatically by the district's eight geographic zones. The

wealthier the area, the more likely students are to have private aides. Among the 238 white elementary school students with autism in Local District 3 on the Westside, 42 percent have private aides. In Local District 5 on the Eastside, just 4 percent of the 560 Latino students with autism have them.

Areva Martin, a special education attorney who has an autistic son, said the statistics reflect not just the ability of wealthier parents to lobby for services, but also an "institutional bias." Based on past experience with such families, schools officials are more likely to offer a higher level of service upfront, Martin said. In other words, affluent, educated parents have paved the way for others like themselves. Martin said she doesn't fault those parents; she just wishes all autistic children had the same opportunity.

L.A. Unified officials offered a similar explanation for the disparity. As parents successfully lobbied for outside aides, the idea spread, and in certain schools it became standard practice to offer them. "Parents learned from each other," said Nancy Franklin, a top special education administrator. "It became a cottage industry in LAUSD." The district is trying to break the pattern by persuading parents that its own staff can meet children's needs in many cases. "We're paying lots of money for services that are of questionable value," said Eileen Skone-Rees, who oversees the district's contracts with companies that supply one-on-one aides.

Pushing back

By the time Jese Castillo was 5, it was clear he was profoundly autistic. But when his mother, Elizabeth, took him to the regional center in South L.A., she was told no help was available, she said. "They told me Arnold Schwarzenegger cut services for the disabled." At his elementary school in South Los Angeles, Jese was enrolled in a special education class and received speech therapy for 30 minutes a week. He made little progress. He could say just eight words, and he never learned how to brush his teeth, draw a circle or put numbers or letters in order. He seemed to have no sense of danger and once nearly ran off the edge of a second-story balcony, his mother said. She pleaded with L.A. Unified officials to provide an aide for his safety. "They said no, because he wouldn't become independent," she said.

A few years ago, some Spanish-speaking mothers with autistic children began meeting in a storage room behind one of their houses. Castillo joined them. At first, they traded tips on communicating with their children. Eventually, they started discussing how to get better services. One mother brought her lawyer to a meeting. The attorney, Edwin Egelsee, takes only cases he believes he can win, knowing that when he does, the district will pay his bill. This spring, he reviewed Jese's records and filed a formal complaint. In an agreement reached through mediation, Jese, now 11, was granted a behavioral aide starting this fall. He has learned to say a few more words: shampoo, open and shorts. His mother hopes he will learn to write his name someday.

"For six years they didn't listen to me," she said of school officials. "I had to get a lawyer."

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Families cling to hope of autism 'recovery'

An autism treatment called applied behavior analysis, or ABA, has wide support and has grown into a profitable business. It has its limits, though, and there are gaps in the science.

Alan Zarembo, Los Angeles Times
December 15, 2011

Third of four parts

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 reported by 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, "forty hours a week" of therapy 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 a valuable marketing tool for the companies that provide ABA. One of the largest firms 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-based Center for Autism and Related Disorders.

Paradoxically, ABA's popularity gets in the way of conducting studies that meet the highest scientific standards. Researchers say many parents are unwilling 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, 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 services 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."

Selling success

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 2 1/2, 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, who went on to 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!!"

Tricky results

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 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.

High expectations

Rhonda Ransdell believes ABA, with the therapists she knows and trusts, is her daughter's best chance to live independently someday, hold a job or fall in love. Morgan 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 tied to close a budget shortfall by eliminating contracts with ABA providers, Ransdell fought successfully to hang on to Morgan's services. "She's going to function at a high level," the mother said. "But you can't put a date on it." Such faith in ABA has led others to disappointment.

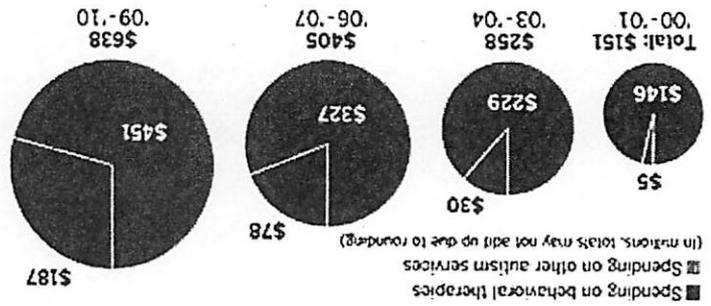
"I used to be one of the believers," said Ryan Reformina, an operating room nurse who lives in Glendale. He has seen the children of friends make great strides. When his own son began therapy more than two years ago, he dared to imagine the possibility of recovery. "Your hopes are up," he said. "Your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

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A preferred treatment gains ground

Applied behavior analysis, or ABA, is the most commonly recommended treatment for autism. ABA and similar therapies consume a growing share of state spending on autism services.



■ Spending on behavioral therapies
■ Spending on other autism services
(in millions; totals may not add up due to rounding)

Source: California Dept. of Developmental Services. Graphics reporting by Alan Zarembo
Data analysis by Sandra Poindexter

Doug Stevens Los Angeles Times

Discovering Autism

Autism hidden in plain sight

As more children are diagnosed as autistic, experts are trying to find unrecognized cases in adults. The search for the missing millions is just beginning.

Alan Zarembo, Los Angeles Times
December 16, 2011

Last of four parts

When autism researchers arrived at Norristown State Hospital near Philadelphia a few years ago, they found a 63-year-old man who rambled on about Elvis Presley, compulsively rocked in his chair and patted the corridor walls. Ben Perrick, a resident of the psychiatric institution for most of his life, displayed what the University of Pennsylvania researchers considered classic symptoms of autism. His chart, however, said he was schizophrenic and mentally retarded. Delving into the file, the researchers learned that as a 10-year-old, Perrick had seen Dr. Leo Kanner, the psychiatrist who discovered autism. In his notes from 1954, Kanner described Perrick as "a child who is self centered, withdrawn, and unable to relate to other people," and recommended that he be committed. Later, other doctors relabeled Perrick. The autism diagnosis was forgotten. The researchers found 13 other patients with unrecognized autism in the Norristown hospital – about 10 percent of the residents they evaluated. It was a sign of how medical standards and social attitudes toward the disorder have shifted.

Over the last two decades, estimates of the autism rate in U.S. children have climbed twentyfold. Many scientists believe the increase has been driven largely by an expanded definition of the disorder and more vigorous efforts to identify it. Scientists are just beginning to find cases that were overlooked or called something else in an earlier era. If their research shows that autism has always been present at roughly the same rate as today, it could ease worries that an epidemic is on the loose. By looking into the past, scientists also hope to deepen their understanding of how autism unfolds over a lifetime. What happened to all the people who never got diagnosed? Where are they?

Like Perrick, who died in 2009, some spent their lives in institutions. Mental hospitals have largely been emptied over the last four decades, but the remaining population probably includes about 5,000 people with undiagnosed autism, said David Mandell, a psychiatric epidemiologist who led the Norristown study. Many more are thought to be in prisons, homeless shelters and wherever else social misfits are clustered. But evidence suggests the vast majority are not segregated from society – they are hiding in plain sight. Most will probably never be identified, but a picture of their lives is starting to emerge from those who have been. They live in households, sometimes alone, sometimes with the support of their parents, sometimes even with spouses. Many were bullied as children and still struggle to connect with others. Some managed to find jobs that fit their strengths and partners who understand them. If modern estimates of autism rates apply to past generations, about 2 million U.S. adults have various forms of it -- and society has long absorbed the emotional and financial toll, mostly without realizing it.

Finally, an explanation

The search for the missing millions is just beginning. The only study to look for autistic adults in a national population was conducted in Britain and published in 2009. Investigators interviewed 7,461 adults selected as a representative sample of the country and conducted 618 intensive evaluations. The conclusion: 1 percent of people living in British households had some form of autism, roughly the same rate that the U.S. Centers for Disease Control and Prevention estimates for children in America today. The British study found it didn't matter whether the adults were in their 20s or their 80s. The rate of autism was the same for both groups. "That would seem to imply the incidence has not changed very much," said Dr. Terry Brugha, a professor of psychiatry at the University of Leicester who led the study. He added that the findings were not conclusive and more research is needed. None of the adults included in the study had an existing diagnosis of autism, though in a few instances relatives told researchers that they had suspected it. In one case, a man said he had asked his doctor about the possibility but was told that a diagnosis in middle age would be useless. After all, he had gotten this far without it.

Still, as more children are being diagnosed with autism, more adults are wondering if they have it too. Karl Wittig, a retired engineer from New York, had always questioned why so few social skills came naturally to him. A diary his mother kept in the 1950s suggests he was not an ordinary child. "This last few weeks, he doesn't pile the blocks anymore," she wrote when he was 2. "He likes to put one next to the other, making a big row of 48." Two years later, he talked nonstop about wires, switches, light bulbs and Thomas Edison. Wittig went on to earn undergraduate and master's degrees from Cornell University and New York University in physics, electrical engineering and computer science. In the research laboratories where he worked, he felt he fit in. "I went into a field full of eccentric people," Wittig recalled. "I was just another eccentric person." Wittig said he eventually figured out how to behave in social situations – to refrain from correcting other people's mistakes, flaunting his math abilities or rambling on about his own interests. He married a former nun 18 years his senior. She died of cancer after two decades together. Wittig described the marriage as happy. Still, he wanted to understand what made him different. So at age 44, he brought his mother's diary to a psychiatrist, who evaluated him and concluded he had Asperger's disorder, a mild form of autism. "I had been waiting for an explanation for these issues my entire life," recalled Wittig, now 55, who lives alone in the apartment he once shared with his wife. "Finally, here it was."

Passing for 'normal'

On the high-functioning end of the autism spectrum, it is possible to pass for "normal," or some semblance of it. Over time, experts say, many people with the disorder adapt to their surroundings. It helps to find a niche, a constructive interest or a job. For some, the key is finding a guardian angel.

Mark Teufel said he could barely survive without Loraine Girard, a divorcee from Texas with whom he has lived for the last 17 years. They met at the Magic Castle, a Hollywood club for magicians. Teufel, 57, who has a wispy beard and gray ponytail, makes contraptions used in tricks – polished works of art crafted from wood and metal. He and Girard live in a rent-controlled apartment in Santa Monica. Tools, spare parts and papers are spread over every

surface, with towers of boxes and plastic bins rising out of the rubble to create an indoor metropolis. It has reduced the hallway to a crawl space, cut off access to one bedroom and rendered the oven unusable. "He needs everything out in the open to know where it is," Girard explained. Teufel said he can't fill out a form, write a check or follow a news broadcast without Girard's help. During a childhood that he described as "full of misery," he said he was often picked on. At home, he would retreat to his room to build toothpick houses or perfect magic tricks. When he graduated from Santa Monica High School in 1973, his father put him to work in the family business, a jewelry factory where he still works part-time, filing and polishing rings. In 1999, his nephew was diagnosed with autism. Urged by his brother, Teufel went to a psychologist, who diagnosed Asperger's disorder and provided counseling for several years. He's adjusted to his condition, he says, even to other people's misconceptions about it. "Most of the time I am treated like I am stupid," Teufel said, "but I am not."

Dealing with curveballs

Howard McBroom might never have been noticed but for a turn of bad luck. His problems early in life – a speech impediment, chronic clumsiness – never raised great concerns, though they led to relentless bullying. He was a decent student and went on to earn a history degree at Indiana University, where he kept to his books and made few friends. After graduation, he moved west and found work as a security guard. For the next 26 years, he worked the graveyard shift and lived in a Burbank apartment. He wasn't bothered by the hole in the floor or the festering mold. He rarely traveled, except for a weekend bus trip once a year to watch an arm-wrestling competition in Petaluma, Calif. As his sense of isolation and depression mounted, he became deeply involved in a neighborhood church. He fantasized about finding a girlfriend or just going on a date, but had no idea how. "I was well aware that I was in a world full of people more capable than me," he said. Then, in 2003, the security company went out of business, and he was unable to find a new job. He fell behind on his rent. He feared becoming homeless. A church member introduced him to an advocate for the disabled, who suggested that he be evaluated to see if he qualified for social services. Nearly half a century into his life, he was told he had autism. "I think I'm somewhere close to the outer range," said McBroom, now 56. "Not severely autistic but definitely not normal."

Graduation from school, the loss of a job, the loss of a parent or any sudden change can unhinge someone with autism. "If there is a curveball thrown, they have trouble reacting to that," said John McGonigle, who heads an autism center at the University of Pittsburgh and who has diagnosed dozens of adults, including, recently, a 76-year-old. "They don't make those adjustments easily," he said. "They don't problem-solve." Had therapies been available when they were children, they might have had better lives, McGonigle said. There has been little research into what kinds of treatment work best in adulthood. McGonigle has been training therapists to recognize and treat the conditions that often accompany autism, such as depression, anxiety and attention disorders. Some people with the disorder simply need a "life coach," he said.

In McBroom's case, once he had a diagnosis, the Lanterman Regional Center in Los Angeles found him federally subsidized housing and a social worker. He started reading books about autism. He reminded himself to make eye contact when he spoke to people. In 2007, he joined

the Lanterman board, representing clients of the center, which arranges state-funded services for the developmentally disabled. One of his priorities is identifying more autistic people who have been missed.

Enormous concerns

Over the next decade, hundreds of thousands of children with autism will become adults. How they will fare – and how much it will cost to take care of them – is a matter of enormous concern for their families and for policymakers. There is another group of people who are at least as needy: Undiagnosed baby boomers who soon will face life without the parents who have always supported them. "Those are the people on the doorsteps of the service system," said Marsha Mailick Seltzer, an autism expert at the University of Wisconsin. "They may not have a diagnosis, but they are there."

An unknown number of families will face the predicament of Kay Duquette, 83, and her autistic daughter, Jeanne, 49. "What will happen to her after I am gone?" said Kay, who is deaf and in failing health. Jeanne's older brother, Doug, a tree care specialist who lives with them in Irvine, said he will eventually be responsible for her. But Jeanne, who receives a monthly disability check, said she can imagine living by herself in an apartment with a few dogs. "Somebody would have to help her with her checkbook," said her mother. "And I don't trust anybody. She doesn't know if a person has good intentions or bad intentions." As a child, Jeanne was taken from specialist to specialist. She was tagged with a multitude of labels, none of them quite right. At first doctors ascribed her difficulties to "slow development" and "extreme shyness." Teachers tried to help. "As you know, difficulty with language is central for Jeanne, and I have encouraged just as much verbalization as possible," one teacher wrote in 1969, when Jeanne was 6. Later came diagnoses of depression, dyslexia and possible paranoia. Doctors and teachers told her mother that Jeanne would eventually catch up. In some ways, she did. At University High in Irvine, she routinely landed on the honor roll, despite her inability to do basic math. On one standardized test, she scored in the 93rd percentile in reading. She played viola in the orchestra and stacked books in the library. She had only one friend – a boy who shared her interest in "Star Trek" – and he moved to Kansas. Making matters worse, her parents were going through a divorce. At one point, she cracked, threatening her parents with a kitchen knife, which landed her in a mental ward for two weeks. Later, she tried college, taking all the writing classes she could. But she dropped out after failing algebra and has lived at home ever since, without friends or a job. Jeanne was 39 when her mother read a newspaper article about autism and took her to a specialist, who diagnosed it immediately. Today she lives for her routines and obsessions: the Civil War histories and fantasy novels neatly arranged on a shelf in her room; the massive jigsaw puzzles she works row by row; chores such as loading the dishwasher and cooking the side dishes for dinner; ESPN "Sports Center" and the sports section of the Los Angeles Times. Her only regular contact with outsiders is when she walks Sakura, her Labradoodle, with neighbors each afternoon. "I just listen to people talk about their lives," she said. Looking back, Kay Duquette wonders how things would be different if her daughter had been diagnosed as a child.

What would her life have been like?

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