

Discovering Autism: Services go to those who fight hardest

December 19 2011, By Alan Zarembo

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.

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 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.

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."

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{ 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.

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."

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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