



Autism's full spectrum

Minority families often miss out on treatment or get left out of research — an ethical failure. New projects are illuminating autism's diverse shades.

BY **AMY YEE** / 4 MAY 2016

ILLUSTRATION BY:
PEP BOATELLA

Each Tuesday afternoon, five people bring their children to Rush University Medical Center, a few miles from downtown Chicago. They come from different parts of the city, from its suburban outskirts to its urban South Side.

For the children, ages 8 to 14, it's a weekly get-together led by two friendly women. The children talk about and practice sharing, asking others to play, dealing with skills such as losing and winning, and also learn to manage stress through deep breathing and other techniques. For the parents, it is a chance for their children to improve their social and communication skills with help from child psychologists. All the children are on the autism spectrum. All but one of the families are black or Latino.

Blanca Escobedo, 43, was born in Mexico and came to the United States in 1975. When her now-13-year-old son was an infant, he did not move in his crib, Escobedo recalls; as a toddler, he seldom spoke. Her son's pediatrician, whose office was in Chicago's gritty South Side, dismissed her concerns and said the boy was lazy. But Escobedo, who has two older sons, says she "knew something was wrong." The boy was frequently anxious and upset. He didn't play with toys, didn't eat well and cried often. "We use to cry with him because we didn't know what he wanted," she says.

She sought out testing for her son, who was diagnosed with autism when he was 2. Escobedo enrolled him in a special-needs school in Chicago that helped with his developmental skills. Since age 5, he has been attending a conventional school, but he still has epileptic seizures, anxiety and attention deficit hyperactivity disorder.

Escobedo, who left school after 10th grade, works as a cashier at a dry-cleaning store in Chicago. Not all of her son's therapies and treatments have been covered by insurance, "but you have to do it," she says. Despite the challenges, Escobedo is relatively fortunate. Her boss gives her flexibility, which is a big help. He lets her close the store and leave work if her son has a seizure, for his medical appointments and for the therapy group at Rush.

Other Latino families struggle even more, she says. "A lot of people don't have papers; they're not legal. They don't advocate for themselves."

Rashaan Meador, a black father whose son is also part of the group, says his son, 8, was diagnosed with autism in 2014. The news surprised Meador because his son had always done well on exams. But it did explain some of his son's behavior — such as obsessively playing video games — and his aversion to group social situations such as birthday parties.

Meador is college-educated and works as a school administrator. He accepted the diagnosis and sought support for his son, but he acknowledges that there is tremendous stigma about any mental condition or disorder in the black community. "Even I had to get it out of my mind that it was something bad," he says. For some parents, getting a diagnosis for their child may not be a priority if they are "worried about food, shelter, basic stuff," he says. Even if they have the interest, some people don't have the time or money to take their children to support groups or treatment, he says.

Escobedo and Meador's stories hint at some reasons why **minorities are underrepresented** in studies of autism and have little access to treatment options. Broad socioeconomic, cultural and language barriers keep minority families from participating in both domains. New studies are delving into ways to recruit and retain minorities in research, as well as developing better screening, support and treatment programs, all of which can bridge the gaps that lead to the exclusion of these groups.

In the context of autism, the term 'minority' may be misleading. Researchers have traditionally believed that autism is more common among white children in the U.S., but this may not in fact be true: A 2014 study found that children of mothers who are black, or immigrated from Central or South America, Vietnam or the Philippines, are **more likely to be diagnosed with autism** than children of white mothers born in the U.S.

What's more, children of black and Latina women born in the U.S. are more likely to show traits of autism, such as impaired language skills and emotional outbursts, than children of U.S.-born white women.

This diversity in autism's prevalence is not yet reflected in scientific research on autism. "Look at who is in a research study," says **David Mandell**, director of the Center for Mental Health Policy and Services Research at the University of Pennsylvania. "The majority are still affluent, white families. We have a long way to go toward reaching minority populations and engaging them in these efforts."

"It's just not fair that some families are not able to get services in our country." –Amy Wetherby

Research divide:

In autism research, minorities have been underrepresented for a variety of reasons. Household structure is one barrier to participating in **genetic studies**. Most typically require DNA samples from parents and siblings of a child with autism, but many black **children don't live in two-parent households** with siblings who share the same parents. (In 2013, **67 percent of black children** in the U.S. lived in a single-parent household, compared with 25 percent of white children.) Perhaps because of this, of the 1,168 families that in 2007 made up the **Autism Genome Project Consortium**, a database of genetic data and clinical information, a whopping 85 percent were of European ancestry. In 2008, blacks accounted for only 2.3 percent of the participants in the **Autism Genetic Resource Exchange** gene bank.

For autism research to be equitable and ethical, these numbers fall far short of where they need to be.

"Research is always an intellectual exercise, but there's also an important social justice aspect to research, especially for treatment and intervention," says Mandell. "Our goal is to make the world a better place. The question then is: for whom? Research says a lot about who you will ultimately make the world a better place for."

Including minorities in research is more than just ethical, however — it is also vital to understanding autism, as different ethnic groups may show different symptoms. Schizophrenia, for example, has genetic **overlap with autism**, and is more common among blacks than among whites.

For some families, the barriers to participation are practical: lack of transportation, childcare or flexible work hours.

Money is another crucial issue. "If there are any costs, that can exclude some minority families," says **Katy Heerwagen**, community outreach specialist at Rush's **Autism Assessment, Research, Treatment and Services Center**.

“Even the expectation that there will be a cost can discourage families because of their past experiences of not being able to access resources,” she says. For these reasons, low-cost programs such as Rush’s therapy group attract socioeconomically and racially diverse families.



Working together: Amalia Contreras (left) of the California-based nonprofit Fiesta Educativa, answers Patricia Sanchez’s questions about her child’s autism.
Photographs by Jenna Schoenefeld

Language also forms a barrier. Non-English-speaking parents must fill out paperwork in a second language and persist through intimidating bureaucracy. Customized resources, such as websites and brochures in Spanish and other languages, as well as access to specialists who speak those languages, can be helpful, Heerwagen says.

Without that help, many minority children don’t even get diagnosed, the first step before participating in research or accessing treatment.

Mandell’s research has found that black children are more likely to have a **wrong or late diagnosis for autism**: on average, more than a year and a half later than white children. Black children are also 2.6 times less likely than white children to be diagnosed with autism on their first visit to a medical specialist. Instead, they are often misdiagnosed with **conduct or adjustment disorder**.

That may be because some parents either are not familiar with autism symptoms or might struggle to describe them in a way that raises a doctor’s concerns. For example, saying, “My child does not appear to

respond to their name being called,” may flag a doctor’s attention more than “My child doesn’t mind me,” as a black parent might put it, says Mandell.

In some neighborhoods, the doctors themselves may be uninformed. Families may have limited access to doctors’ time, and the interactions may be cursory. “Especially in impoverished communities, the consistency of care is not so great,” says Mandell. Doctors in those communities might be overburdened and neglect to explore subtle symptoms — or might even think autism is a “white disease,” he says.

Minority children with autism are also **less likely to receive specialty care** for gastrointestinal conditions, sleep disorders and **epilepsy**, all of which are associated with autism, than are white children, according to a 2013 study in *Pediatrics*.

Cultured science:

In an effort to bridge these gaps, many research teams are reaching out to minority groups in ways that are more attuned to culture, language and community.

One team, based at Children’s Hospital Los Angeles, has zeroed in on some of the barriers minority families face in participating in research — and has come up with innovative solutions. With the goal of recruiting Latino children with autism for a study on gastrointestinal conditions, the researchers partnered with a Los Angeles nonprofit that works with the Latino community. The study, published **in February**, included 97 children with autism between 5 and 17 years; more than 82 percent of the participants were Latino, and the parents tended to have low incomes and education levels.

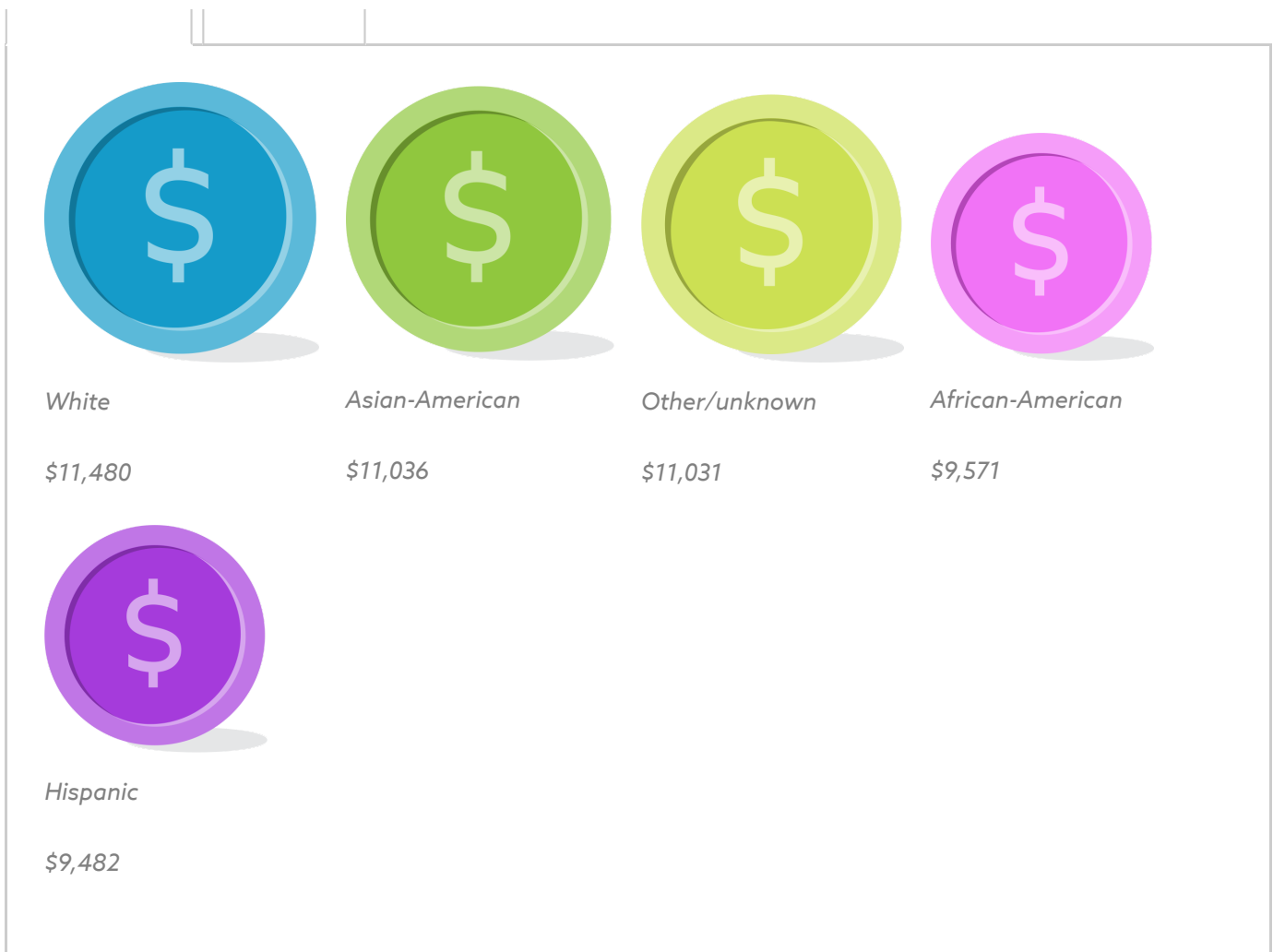
In many autism studies, researchers post flyers in clinics to recruit participants. However, the team realized a passive approach was not going to be effective in this community. Instead, they held information workshops at community centers and reached out to people through the Mexican consulate. The workshops were not specifically about recruiting children for the study, but rather meant to raise awareness so families could “understand the work we do,” says **Irina Zamora**, assistant professor of clinical pediatrics at the hospital.

In small groups at the community centers, the researchers explained to the parents the basics of autism — for example, why the children might act differently than others. They also covered general topics such as mental health and nutrition. “Parents know children have tummy problems, but they might not know they are related to autism,” says Zamora. The parents also had the chance to meet other families with autism in a supportive environment.

The color of money

Different dollars: Data from the state of California, which subsidizes autism services, reveal a sharp divide: Per-capita spending for whites is far higher than for other racial groups, a gap that grows wider in adults. The numbers, from 2013, reflect nonmedical spending: therapy, education, transportation and residential care.

CHILDREN	ADULTS
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Source: Leigh J.P. et al. PLOS One 11, e0151970 (2016)

Some families questioned the need for blood and saliva samples and were reluctant to subject their children to pain from a blood draw. Others were concerned about whether friends and neighbors would learn about their child's condition. "The families want to know: 'What are they going to do to my child? How many hours will it take? What are they going to do with the biospecimen?'" says Zamora. The team assured families that information would be kept confidential. Spanish-language interpreters and Zamora, who is bilingual and of Mexican-Cuban ancestry, simultaneously translated the group sessions. The researchers also translated their presentations, surveys and pamphlets into Spanish to help demystify the research.

"People want to know who you are," Zamora says. "Working with them made a difference in understanding the needs of the community, and then helping to support families."

The researchers gave each family a \$25 gift card after each study visit and compensated them for transportation, but ultimately, it was the trust they built that helped make the project successful, Zamora says. For example, one parent who had participated in a previous study she led persuaded 21 parents to sign their children up for the gastrointestinal project.

Once studies are complete, participants should also have access to the results — an issue the families brought up. A separate study led by researchers at the University of Southern California in Los Angeles aimed to identify ways to **disseminate scientific information to low-income Latino families** with a history of autism.

Graduate students in a nonprofit science education program distilled scientific articles that were translated into Spanish by certified translators and reviewed by a partnering community organization for cultural and linguistic nuances. With help from the community organization, the researchers recruited families to read the translations and give feedback; 90 percent of the participants said they wanted to read more briefs.

Other teams are also trying community-based approaches. A group of researchers led by **Amy Wetherby**, director of Florida State University's Autism Institute, is reaching out to black families through churches and other grassroots organizations. Their goal is to work with the **National Black Church Initiative**, a network of 34,000 churches, to find ways to diagnose and treat minority children with autism at earlier ages. "Even people not actively going to church are still connected to them," says Wetherby.

In 2015, the National Institute of Mental Health granted \$10.4 million to Wetherby's team for this project. Government agencies have historically funded hard-science research, but community-based research has become a new priority, says Wetherby. "We have children out there that we need to reach," she says. "We need to understand that process better."

Wetherby and her collaborators on the East Coast of the U.S. plan to screen 9,000 children in each of four states: Florida, Georgia, Pennsylvania and New York. The project aims to eventually identify roughly 400 children with autism.

Last year, the researchers conducted meetings with minority families and healthcare providers to better understand the barriers to early detection of autism. They found that parents often don't know how to identify autism. They may know that a child should talk by a certain age and have certain motor skills, for example, but might be unaware of the importance of gestures. The team has developed a website called **First Words** as a general resource for parents to learn about developmental milestones. The researchers plan to present findings from the project at the International Meeting for Autism Research later this month.

For the project's next phase, the researchers have started screening children in Fort Myers, Sarasota, Naples and surrounding rural counties in Florida, including Immokalee, a largely Latino farming community.

They aim to educate child development specialists in churches using **Autism Navigator**, a Web-based course developed at Florida State University's Autism Institute. The idea is for specialists to raise awareness about autism at Sunday church meetings and invite families with children between 9 and 18 months old to be screened. The researchers also plan to train staff in participating doctors' offices to recognize autism symptoms.

"It's just not fair that some families are not able to get services in our country," says Wetherby. "We know how to do [early intervention]. We need to get the resources out."

"We have a long way to go toward reaching

minority populations." –David Mandell

Combating stigma:

Most autism research on minorities focuses on blacks and Latinos. But Asian-Americans also experience cultural, language and socio-economic barriers, says **Christina Kang-Yi**, research assistant professor of psychiatry at the University of Pennsylvania Perelman School of Medicine.

A **2011 study in South Korea** by a team based at Yale University found that nearly two-thirds of one group of urban children with autism **had not been properly diagnosed**. Kang-Yi's team hypothesized that because many Koreans in the U.S. are foreign-born, there are likely to be many undiagnosed Korean-Americans with autism as well. (Roughly 70 percent of the 1.46 million Koreans in the U.S. were born in Korea and speak Korean at home.)

In a study published last year, Kang-Yi and her collaborators **interviewed people in Korean communities** in Queens, New York, and the Washington, D.C., area, including parents and child health and education specialists such as teachers and doctors. At the Child Center of New York in Flushing, Queens, they found that applications for general counseling services have risen sharply in the past two decades, from 250 in 1993 to 1,700 in 2012. But schools, not families, initiate most inquiries. Parents have little experience advocating for themselves in schools, the researchers found.

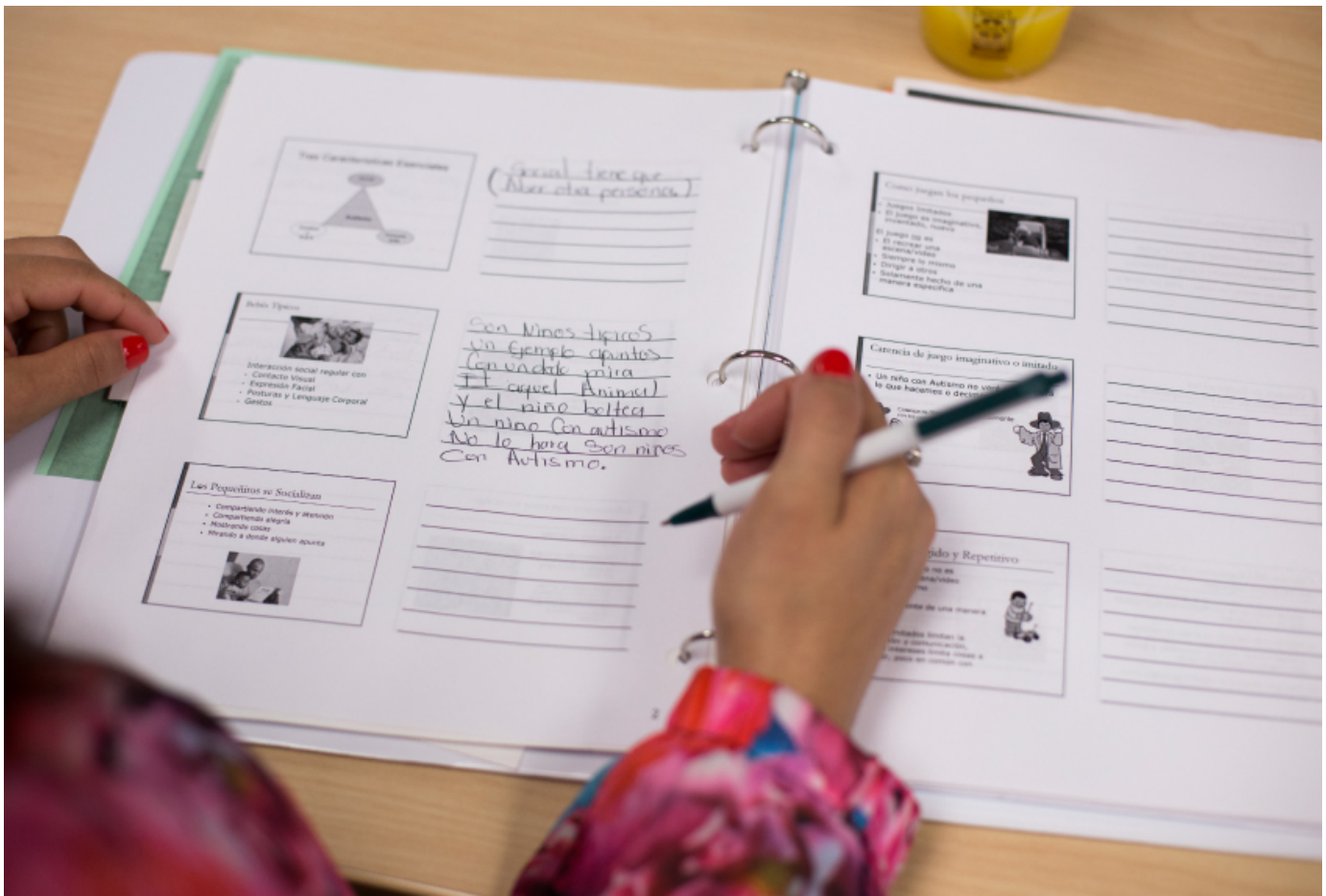
The researchers' interviews with Korean mothers suggested a strong stigma surrounding autism and social isolation for both children and their families. A social worker and a physician with the Korean Behavioral Health Association described several adults with autism who were not diagnosed until after high school. One physician cited in the 2015 study described Korean families as having "a high tolerance for inappropriate behavior' — as long as the individual is hidden from public view."

Mandell, a co-author on the paper, says the Korean community "brought up the idea of stigma and shame more than any other community I've worked with. There's a lot of concern at even hinting that something is developmentally wrong with their children."

Health and education specialists interviewed for the study named fear of medication as the biggest barrier to care in these families. The researchers also highlighted parents' misperceptions about autism, such as the idea that bad parenting or home environment or lack of love was a cause.

With these perceptions in mind, the team adapted the widely used Autism Speaks '**100 Day Kit**' for the Korean community. This version added statements such as: "In the past, some doctors in the U.S. wrongly believed that the mothers of autistic children were emotionally cold and did not love their children." The tool kit, designed for the first 100 days after diagnosis, had previously only been translated into Spanish.

***New know-how:** The Fiesta Educativa education program helps parents learn more about autism — including finding the right therapy and advocating for their children.*



The researchers also adapted vocabulary and softened the phrasing in the Korean translation because mothers in the study were uncomfortable with emotional wording. “You may feel completely overwhelmed,” was translated into Korean as: “Many families are confused.” They replaced concepts such as “intervention” with the Korean word for “treatment,” and changed “outrage” to a Korean word for “upset.” They also addressed other misconceptions raised during interviews with Korean mothers, such as the idea that children cannot be diagnosed with a developmental disorder before age 3.

Korean parents, worried about privacy, may be reluctant to attend informational meetings specifically about autism and unlikely to pick up brochures about autism in clinics, daycare centers and churches, Kang-Yi says. Instead, health and education specialists advised the researchers to distribute information about general developmental milestones and education — common concerns for Korean parents — rather than focusing on autism. By doing so, they could indirectly raise awareness about autism through Korean newspapers, online groups, daycare centers, churches, grocery stores and cafes.

Unexpectedly, the researchers found that Korean church leaders are familiar with developmental disorders, says Kang-Yi, herself born in Korea and fluent in Korean. Pastors are trusted in the Korean community and are an important source of emotional support and information for families. Sometimes they connect families to Korean physicians in church congregations.

Kang-Yi says more needs to be done to connect mainstream autism organizations such as **Autism Speaks** with leaders in the Korean community. “As researchers, we should study and identify how we can sustain this kind of program. It shouldn’t end with a research project,” she says.

This kind of help and information can be invaluable for raising awareness about autism among many minority groups. In Blanca Escobedo's case, for example, when specialists returned with a diagnosis of autism for her son, it was the first time she had ever heard the word.

Even though her pediatrician had brushed off her concerns, Escobedo was determined to find out why her son wasn't speaking. She sought help from specialists, who diagnosed her son.

With their guidance, she enrolled him in a special-needs school at the University of Illinois at Chicago. Thanks to one-on-one instruction and other support, her son gradually learned to speak, interact and cope. "When he gets the right thing from the right person, he's a totally different kid," says Escobedo. "If I had listened to my first doctor and didn't do a speech evaluation, [my son] would not be able to speak or do all the things that he does. You have to knock on doors, calling, pushing. But it's what we have to do for our kids."

Escobedo's sister-in-law had a different experience with her own son, who displayed similar behaviors as a baby. When Escobedo suggested her nephew might have autism, her sister-in-law "got very upset and started screaming at me, 'Don't ever say that!'" she recalls. Her nephew was eventually diagnosed with autism but only got special education and support services when he was older. He is making progress, Escobedo says, but his speech is still limited.

After her son was enrolled in the special-needs school, Escobedo took brochures about autism to the pediatrician who had rebuffed her. She remembers telling him, "My son is not lazy. If you have more patients like my son, help them." The doctor put the brochures on his counter. "He said, 'I'm sorry I couldn't help you before, but thank you for the information,'" Escobedo recalls. "Hopefully, he can help another parent."

