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Autism's silent taboo



PHOTOS BY JONATHAN YOUNG - jyoung@charlotteobserver.com

Steve Aguilar, 8, draws back for a swing at a piñata during a recent party in Charlotte for a summer school run by World Alliance for Families and Children. The program assists immigrants and minorities with autistic children.



Mariame Boujlil pulls apart the piñata as children scatter at her feet to pick up the candy. Boujlil's son Zachary, 5, is autistic.



Dorian Peele, 5, bangs on a toy drum during the party. In North Carolina, an average of at least two children are diagnosed with autism every day.

Immigrant children may come from cultures that treat the condition with shame and secrecy. But a Charlotte mom is helping parents cope.

BY KRISTINE CRANE
kcrane@charlotteobserver.com

Learning your child has autism is hard for any parent – especially if you're an immigrant adjusting to a new medical culture in the U.S., while fighting prejudices back home that your child might be cursed.

Mariame Boujlil, a native of Morocco who now lives in Charlotte, struggled with that three years ago when her son Zachary, then 2, was diagnosed with autism. In Morocco, talking about autism is taboo, she said. She knew she couldn't ignore the problem like people in her home country. But she didn't trust the American approach that often calls for prescription drugs.

Immigrants and minorities in the U.S. with an autistic child can feel caught between two cultures. To help parents like herself cope, Boujlil started a support group.

The group, World Alliance for Families and Children, helps parents navigate the U.S. health care system and provides information on treatment options. It also runs a summer school geared to their needs.

Autism manifests itself with several different abnormal behaviors. Usually, it hampers personal communication skills

and interaction. Doctors sometimes interpret signs of the disorder in immigrants and minorities as cultural confusion.

Boujlil says before Zachary's diagnosis, his doctor dismissed her concerns that her son didn't talk and rejected her hugs. "The doctor told me, 'That's OK: You speak Arabic, French and Spanish. Your child is just confused,'" she said.

But Boujlil, 44, knew better: Before founding her organization, she had worked as an interpreter for Middle Eastern, North African and Hispanic families with autistic children, and recognized the signs.

Fighting shame and denial

Boujlil recalls a mother from the Middle East who said she didn't want anyone in the Arab community to know her child had autism. Another mother from Egypt with whom Boujlil worked told the doctor who had just diagnosed her son with autism: "We believe in God; he'll be OK." She told the social worker her son needed rest, not the camp the social worker had suggested.

In certain immigrants' cultures, parents see autism as a hidden burden, says Roy Richard Grinker, an anthropologist

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Charlotte mom and group fight taboo

AUTISM

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at George Washington University who has researched autism in immigrants. That makes it hard for them to seek care in the U.S. "They may mistrust the medical establishment and have fears about privacy," he said.

But often, they grow accustomed to a more open-minded mentality in the U.S., Grinker said. "Immigrant Americans are feeling more quickly empowered here," he said. "One of the great achievements we've had in the U.S. is people are starting to talk more about autism."

Experts say earlier diagnosis of children with autism – preferably before age 3 – often leads to better outcomes.

Help in Charlotte

Esmeralda Garcia feels more supported and informed about autism in Charlotte than she ever felt in her native Mexico. When her 6-year-old daughter, Mariane, was diagnosed four years ago in Garcia's hometown of San Luis Potosi, Garcia, 30, had never heard of autism.

After a year of treatments, Mariane hadn't improved. Garcia decided to move back to Charlotte, where she had emigrated with her husband some years before, so Mariane could get better health care.

Garcia saw an ad for Boujlil's group in a Spanish language newspaper and called Boujlil, who took her to the doctor and later helped enroll Mariane in school.

As Mariane played with other kids at a recent summer school party, her mother recalled the days when her daughter wouldn't talk to anyone. Medication has helped a lot, Garcia said.

Some autistic kids are hyperactive. Boujlil's son, Zachary, ran from room to room at the



JONATHAN YOUNG - jyoung@charlotteobserver.com

Mariame Boujlil's son Zachary, 5, eyes a candy-filled piñata at the party for the summer school run by World Alliance for Families and Children.

summer school party. He stopped to tear open a packet of Oreo cookies with his teeth and then threw the cookies on the ground.

But he has improved from the days when he would "just stare at a wall," his mom says. Since Boujlil didn't want to put him on medications that she feared might deaden his personality, she put him on a gluten-free diet. He also went to speech therapy and will soon start behavioral therapy.

Empowering others

Zachary's progress has also improved Boujlil's life. She's in a culture where she can follow scientific developments about her son's disorder instead of just feeling victimized by its

consequences, she said.

Part of her group's mission is to empower other parents.

Shirley Araya, who talks to Boujlil frequently, felt relieved to know what was wrong with her son when he was diagnosed with autism three years ago. But she was also depressed.

"We didn't even go to the supermarket, because I was so ashamed that my son would be screaming," she said.

Araya put four locks on the doors of their family home in Statesville because Matthew kept running to the nearby lake. (Drowning is a leading cause of death among people with autism, according to studies). She put away all valuable objects because he was break-

Battling misdiagnoses

Experts say the earlier a child with autism is diagnosed, the better.

But professor David Mandell of the University of Pennsylvania School of Public Health found that minorities in Philadelphia are typically diagnosed with autism about one year later than whites. He believes that it could be proof of a national problem.

The most typical misdiagnosis preceding autism among African Americans was conduct disorder; it was adjustment disorder among Hispanics.

In another study Mandell conducted, kids in families with little or no spoken English were three times less likely to be referred by physicians to early intervention programs.

Mandell said early diagnosis can prevent harmful situations. For example, sometimes autistic kids are placed in correctional facilities, he said. "An autistic kid is a natural victim. The last thing you want to do is put them in a classroom of natural bullies."

ing things.

Araya, a native of Costa Rica, educated herself about autism. She realized treatment could improve his condition and she stopped trying to hide his autism from others.

That attitude made it easier for her to accept her 3-year-old daughter recently being diagnosed with autism. Araya laughed when she said her house now looks like a day care center, with instructions telling her children how to brush their teeth and flush the toilet.

"I don't care anymore that I have signs on my toilet, shower, all over my walls," she said.

In North Carolina...

On average, at least two children are diagnosed with autism every day.

An estimated 50,000 families in the state have a child or other family member with autism.

Between 700 and 800 school kids each year are diagnosed.

The number of students with primary autism has more than tripled in the past seven years.

This student population is growing 17 percent to 18 percent, compared with 2 percent to 3 percent for the total student population.

Experts say diagnoses typically increase in areas where awareness of the disease and diagnostic services are growing.

Source: N.C. Public Education Statistics Profile, 2007 edition.

For more information, contact the Autism Society of North Carolina: www.autismsociety-nc.org, or call 800-442-2762.

Spanish speakers should ask to speak to bilingual parent advocate Mariela Maldonado.

To reach parent advocates in Charlotte, call 704-894-9678.

The Autism Society of North Carolina has an extensive bookstore with many books in Spanish; it also orders books in other languages. Visit the Web site at www.autismbookstore.com

To contact the World Alliance for Families and Children: 704-618-1489, or mariame200lus@yahoo.com

WAFAC's annual fundraiser, "Cinturón del Mondo," to celebrate its third anniversary, is Sept. 13 at 4835 S. Tryon St. in Charlotte.

"Autism's Silent Taboo" by Kristine Crane

When I was working on the first article I wrote for the Observer, on a natural healing festival, I called up Miriam Boujlil, who was going to have a booth on her autism organization at the festival. As she started talking about her own struggles as an immigrant parent with an autistic child, and those of the people in her group, I sensed there was a larger story there. Autism is a hot topic, but we rarely hear about the cross-cultural interpretations of the disease. I discovered talking to Boujlil that it's a highly stigmatized disease in many cultures. Immigrants find themselves in an especially difficult situation--on one hand, fighting against prejudices in their home cultures, and on the other, struggling to negotiate their needs in a medical system that is new to them, in the U.S.

I started doing some background research on autism and multicultural issues, and discovered it is a topic that scientists are starting to explore. When I went to the healing festival that first took me to Boujlil, and met both her and her autistic six-year-old in person, I knew she'd make a good profile. A few weeks later, she invited me to the inaugural party and meeting of her support group for parents with autistic children and their kids, where I did much of the reporting.

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