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Parents of children with autism: We struggle alone

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Her day might begin at 2 or 3 in the morning, when her 9-year-old autistic daughter, Ashlyn, wakes up next to her. And from that moment on, Jackie Polvado's life is a full-out sprint.

"Ashlyn still sleeps with me because it's the only way we can get any sleep. But I've been up day and night, like when my daughter was up for 48 hours, screaming," said Polvado of Keller.

"It's exhausting, and there's no end in sight."

For families with children with autism spectrum disorders - a range of developmental disabilities that cause social, communication and behavioral problems - each day can be emotionally overwhelming, stress-filled and isolating.

Family and friends shy away. The child's behavior can leave parents prisoners, trapped at home. If they venture out, passers-by stare, wondering why the child isn't under control.

"Sometimes, the parents think they're admitting failure when they ask for help," said Shanel Tarrant-Simone, the single mother of twin 10-year-old autistic sons. "I'm the parent; I should know how to deal with it."

"But no parent is equipped to do this."

And while neither of these moms could imagine hurting their children, they can begin to understand the hopelessness Saiqa Akhter may have felt when she allegedly killed her two children in Irving last month, or how overwhelmed a single mother in New York was to kill her 12-year-old autistic son and then herself.

"People on Facebook were very quick to say, 'Oh my God, how could she do this?' But I say, how did she get to that point?" said Tarrant-Simone of Frisco. "The isolation and hopelessness - I've felt them."

Still, nothing can excuse what these women did, Polvado said.

"The resources are there - there aren't enough of them, and they cost money, but there is help," she said.

But day in, day out, many families with autistic children say they struggle on alone.

"We don't have other friends coming and offering to babysit our children," said Clay Boatright of Plano, with wife Carole the parents of three daughters, including autistic 10-year-old twins. "They don't have friends inviting them over for sleepovers. What we have is people saying, 'Wow, that must be tough.'"

Years of waiting

Unfortunately, the number of ASD cases is soaring. Statistics from the U.S. Centers for Disease Control and Prevention say almost 1 percent of children have autism or another ASD. Diagnoses in Texas increased 400 percent in the past 10 years, a trend that has officials searching for ways to teach affected students - and pay for it with the state facing a budget shortfall of up to \$18 billion.

Meanwhile, tens of thousands of people with developmental disabilities in Texas spend years waiting for assistance.

"We're at 300-and-something now," said Tarrant-Simone, "and we've been on the list for five years."

Boatright said it takes about eight years on average to get to the top of an assistance list, depending where you live in Texas.

Dr. Catherine Karni, an associate professor of psychiatry at the University of Texas Southwestern Medical School in Dallas and medical director of the outpatient clinic at Children's Medical Center Dallas, said some of the increase can be explained by a broader definition of the autism spectrum, which includes Asperger's syndrome, Rett syndrome and childhood disintegrative disorder.

"So you have severely autistic children and others with something that doesn't show the full symptoms of autism," Dr. Karni said. "You have more people."

More awareness of autism and better diagnostic tools also increase the numbers.

"But most likely, there is an increase in prevalence. We don't know how much, or why. We believe there is a genetic component - all the research points to that, and this tends to aggregate in families," she said.

Some speculate that environmental pollution can be a contributor. Others blame childhood immunizations, though research hasn't shown any clear correlation, Dr. Karni said. Certain metals that used to be a part of vaccines have been removed, but cases of autism continue to increase.

With the causes unclear, there is no cure. "We have different treatments. We have behavioral treatments. We use medications in psychiatry that might help with specific symptoms," Dr. Karni said. "But they don't cure autism."

Early diagnosis critical

Early diagnosis and treatment are currently the best ways to bring improvements, Dr. Karni said.

"Our clinic goes down to 12 months of age, because the earlier the diagnosis and intervention, the better the result," she said.

"It's a small window of opportunity - a child's first five years - because of the plasticity of the brain at that age," she said. "After the fifth year, the results are not as good."

But getting an early diagnosis can be difficult.

Tarrant-Simone's sons were born prematurely, but were home within 11 days and showed all the normal signs of progress except for speaking.

"At 12 months, it just wasn't coming along," she said. But when she pointed it out to their pediatrician, she was told, "They're boys; they're preemies."

"You're a mom - you know something is wrong with the child," she said, "but they were doing all this other stuff - smiling, laughing, interacting with each other. So a lot of the concerns I raised were just swept under the rug."

Polvado's daughter was social, too, and developmentally advanced. She had no problems with language. "Her first word was 'cat,'" her mom said. But there were mild signs at an early age - she hated the sound of laughter, even as an infant.

"Then it was a slow progression," Polvado said. "She started obsessing on eating only certain foods. And her language was slowing down. It wasn't functional. She could say 'cat,' 'dog,' 'shoe,' but she would never say 'juice' because she was thirsty.

"I knew something was wrong and asked my pediatrician about it, and he said don't worry about it. Everyone said nothing was wrong."

The American Academy of Pediatrics has worked over the last few years to educate pediatricians on ASDs, Dr. Karni said.

"Obviously, a child who doesn't talk may have other things, too, so it isn't easy to make this diagnosis," she said. "The important thing is to send the child to specialists. Pediatricians need to have their antenna up and refer these cases."

But if that doesn't happen, she said, parents need to find services on their own.

'Happy and healthy'

Even if the diagnosis comes too late for early intervention, parents like Boatright believe that appropriate kinds of education can provide the life skills their children need.

"As kids are diagnosed and progress through the school system, we need to identify what their true skills and talents are," Boatright said. "What are their strengths? What do they like to do? How can that be enhanced and made marketable?"

The need for proper programs is a national issue that needs immediate attention, said Rita Shreffler of Nixa, Mo., executive director of the National Autism Association.

"Almost 1 percent of the kids in this country have autism," she said, "so what do we do?"

"A study a few years back said the lifetime cost of care for individuals who need round-the-clock help is \$3.2 million," she said. "I don't think people realize that 1 in 110 children or even more have an ASD, and they're coming of age. So it's important that we find treatment."

"Otherwise, this will fall to the taxpayers, at \$3.2 million each."

Naturally, the future hangs most heavily on the parents of autistic kids.

Will there be a cure someday? Who will care for their child when they are gone? Can the child find friendship, happiness?

"I have a motto in my life: There's no such thing as false hope," said Polvado, who with her husband, Lamarque, publishes a magazine called Connections Kids to provide a list of available services. "I hope for the best. I hope Ashlyn will recover and find her dream job, get married and have children. That's always going to be my hope.

"Then, of course, there's reality. The reality is we may not achieve that. So we take it day-by-day, hour-by-hour. I'm hoping for recovery, I'm working for recovery. But if in 10 years she can function but needs assistance, I'm OK with that.

"I just want Ashlyn to be happy and healthy." AUTISM NUMBERS

•Roughly 1 percent of children in the United States - 1 in 110 - have an autism spectrum disorder, with developmental disabilities running from slight to severe.

•ASDs occur in children of all racial, ethnic and socioeconomic groups, but disorders are four to five times more likely in boys than girls.

•Studies of identical twins show that if one has an ASD, the other will be affected 60 percent to 96 percent of the time. In nonidentical twins, if one has an ASD, the other is affected 0 percent to 24 percent of the time.

•Parents who have a child with an ASD have a 2 percent to 8 percent chance of having another affected child.

•A 2009 report showed that 41 percent of children with an ASD also had an Intellectual Disability - an IQ of 70 or below.

•About 40 percent of children with an ASD don't talk at all, and an additional 25 percent to 30 percent have some words at 12 to 18 months of age and then lose them. Others may speak, but not until later in childhood.

•On average, medical expenses for someone with an ASD are about five times higher than for those without an ASD.

SOURCE: U.S. Centers for Disease Control and Prevention

Resources

Many websites offer information on ASDs, from support groups and service providers to age-specific information that could help indicate whether a child has a disorder.

U.S. Centers for Disease Control: www.cdc.gov/ncbddd/autism/index.html

Autism Society of America: www.autism-society.org/

Dallas Chapter: www.autism-society.org/dallas_chapter

Collin County Chapter: autism-ascc.org

First Signs: www.firstsigns.org

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