

ABOUT AUTISM

## Scientists search for new answers about autism

*Bad mothering and vaccine theories rejected*

By Daniela Lamas  
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Edited by Laini Onyeanus

A baby grabs a toy, plays, then looks up at her mother, following her with her eyes when she turns around.  
Children with autism lack these developmental steps.

"Kids don't look up. Why? It's not as pleasurable," said Dr. Peter Mundy, a professor of psychology and executive director of the University of Miami's Center for Autism & Related Disabilities. "And if they don't, they end up developing differently."

Decades after doctors blamed autism on poor mothering, scientists are unraveling the brain's mysteries to understand the genetic disorder. Some theories focus on flawed chemicals within the brain; others, like Mundy's work, look at the brain's structure.

One area is the cerebellum, which helps coordinate visual attention and movement. If you ask an autistic child to pay attention to something, he often won't, Mundy said.

"Autism's problem is having a sense of your body in space, who am I, and where does my body begin, how do I negotiate my way around a room?" said Dr. Janice Lindsay-Hart, a Baptist Hospital psychologist specializing in autism.

The brain's temporal lobe, involved in "social perception" like eye contact, understanding expression and processing faces, is also thought to be affected, as is the part that processes others' feelings.

Children are less likely to develop communication skills if they can't think about another's perspective, Mundy said. The resulting isolation could lead to hand-flapping and repetitive behaviors, he added, noting that orphans act similarly when deprived of stimulation.

Autism has a strong genetic component. Studies have shown that children in a family affected by autism are more likely than the general population to have the disorder. Researchers are exploring five chromosomes that appear linked to autism, and estimate as many as 30 genes could be involved, according to Exploring Autism, a Web site funded by the National Alliance for Autism Research.

One possible environmental cause, vaccines with a mercury-containing preservative, thimerosal, was first proposed in a 1998 study published in the *Lancet*. This study linked autism to the measles, mumps and rubella (MMR) vaccine, using studies of parents whose children became autistic following their vaccines. Recently, however, 10 of the 13 scientists retracted their conclusion. (Most vaccines no longer contain the preservative.)

Another study, published in *Pediatrics* in September, analyzed three decades of data from Denmark and didn't find any connection between thimerosal and autism.

A meeting convened in February by the Washington research group, Institute of Medicine, reviewed this study, but won't release its report for months.

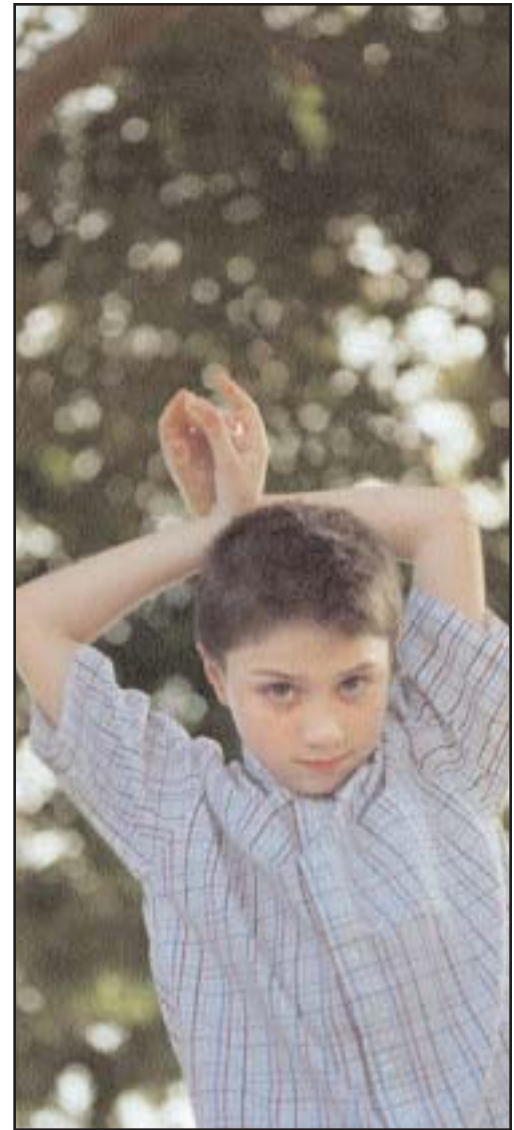
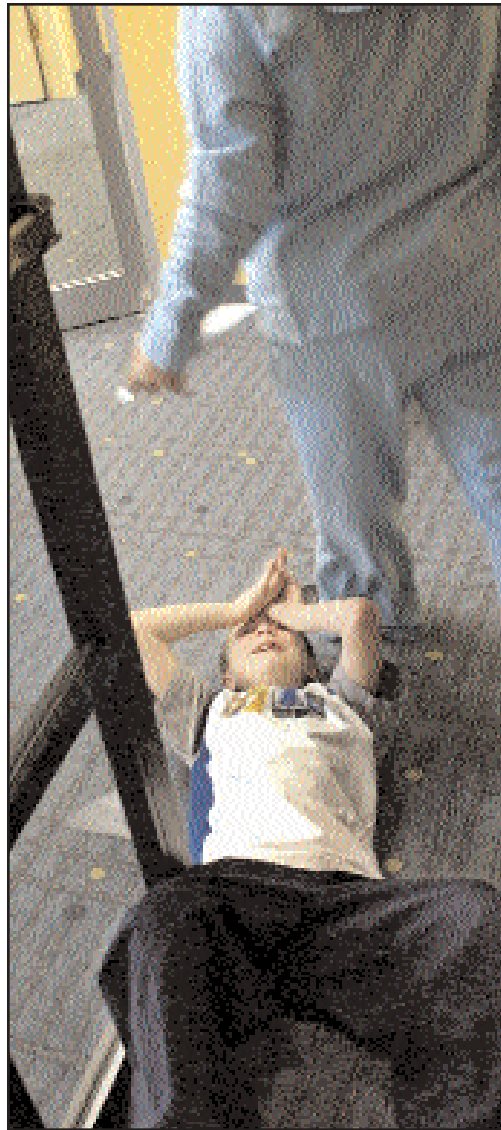
"When I look at the science, does it seem to show a connection? I'm skeptical," said Dr. Michael Alessandri, who directs UM's Center for Autism & Related Disabilities.

Much of the vaccine link is a question of timing: After a social first year of life, autistic children get vaccinated and begin to regress between 12 and 18 months of age, losing language they've acquired.

"There is so much we still don't know," said Hilda Mitrani Bennett, whose 9-year-old son David, is autistic and who reacted to his vaccines with diarrhea, a rash and high fever. "What we know is that it's not an acceptable risk for a child to end up with autism instead of measles. Anyone who's lived for 24 hours with a child with autism will tell you that."

# A U T I S M

Frustrating    Fragmented    Isolated



AP Photo

**Lead-in:** David Bennett, 9, is upset when his mother tries to get him to leave, left. David has autism and is shown next with Stacie Rubin Smith, a speech-language pathologist, and then playing after therapy at the South Miami Hospital's Child Development Center.

## As the number of those diagnosed with autism grows, schools and parents seek alternatives for reaching children

By Daniela Lamas  
Knight Ridder Newspapers  
Edited by Molly Freedman

David Bennett sits in a doctor's office, surrounded by little action figures, spaceships and plastic food. He chooses a banana and speaks in a sing-song voice. "Take the banana to the queen."

"Who's the queen, David?" asks his mother, Hilda Mitrani Bennett, using exaggerated curiosity to capture her son's interest. Then, "what should the queen do with the banana, David?"

It is deconstructed play, with the weighty goal of trying to engage the 9-year-old and draw him from the frustrating, fragmented and isolated world of autism.

"David has progressed a lot. He's recovering some of his bubbly personality, but there's a sadness that's hard to overcome. And there's a sadness I feel as a parent for what could have been," Bennett said. "It's like a living death of the infant I knew."

Her struggle resonates with an increasing number of families.

Two decades ago, 14 in 10,000 children suffered from autism and related disorders, a neurological condition that severely affects communication, social and motor skills. Today, the number has soared to six in 1,000 children, with four times as many boys as girls likely to be stricken, according to the national Centers for Disease Control and Prevention. It's generally apparent by age 3.

There's no cure, but therapy and medication allow some to become independent, go to college, get married. Others remain trapped by their symptoms, which can include self-destructive behaviors like head-banging or hand-flapping.

The science remains murky, as researchers work to understand the brain function responsible for the genetic disorder. But they're divided over the source of the rising numbers; some point to increased diagnosis, others to an environmental trigger, like vaccines. The National Institutes of Health funding for autism research jumped eightfold in the past 10 years, to \$81 million in 2003.

CDC is funding studies to determine the inci-

dence of autism in 11 locations nationwide.

They'll find families like Curtis and Regina Anderson, whose quest to get 4-year-old Maya talking forced them to file for bankruptcy. Or Isabel Meister, struggling to home-school funny, musically talented 10-year-old Samuel because there's no classroom he'll tolerate.

Cause aside, say parents and doctors, the health care system and schools simply aren't ready to handle the 14,000 to 15,000 autistic children and young adults in the state.

"Frankly, when it comes down to it, a lot more research needs to be done," said Dr. Marygrace Yale Kaiser, coordinating the University of Miami's Center for Autism and Related Disabilities CDC program. "There are lots of people who are affected already, and what caused it or not is a moot point. They have it, and we need to know the ways for them to have the best outcomes possible."

There are 1,300 students diagnosed with autism in the Miami-Dade County public schools; just over 1,000 in Broward. Gulfstream Elementary in South Miami-Dade has 12 programs for autistic children, up from two when

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## In Xanadu did dads and moms meet, relax

By Kathleen Megan  
The Hartford Courant  
Edited by Joan Solsman

If you've ever been home alone with small children, you know there are those days — particularly cold, rainy, gray ones — when you need to get out of the house before someone gets hurt.

But perhaps your friends work and your relatives are several states away. Where do you go?

Christine Jackson knows just the place. It's not a day care center or a nursery school. It's a kind of family club in Hamden, Conn., called

Xanadu, where parents can go with their children age 5 and younger.

On a recent morning, Jackson sat on a comfortable couch sipping coffee while her children, David, 3, and Peter, 2, chased each other round and round through a play tunnel.

"I can get a cup of coffee, and they can play," said Jackson, who lives in Hamden and enjoys the time to talk to other mothers.

"I'm 44. I started pretty late with kids, and it's hard with my friends. They get tired of hearing me talk about toddlers," she said. "Here, you

can go on and on about potty training, and nobody gets bored."

Katherine McNulty, of New Haven, said that when she quit her job to stay home with her daughter Lucy, she felt pretty isolated. "We had moved here for my husband to go to grad school, and I really didn't know anyone," she said.

Now she comes twice a week to Xanadu, and her husband comes on Saturday morning. "It's so nice to hang out with other adults, even if it's just sitting next to them on a couch reading a magazine," said McNulty.

Amy Mason-Mann, who started Xanadu 18 months ago, was an early-childhood educator and a new mother herself when she had the idea. When her son, Xander, was 7 weeks old, she began to take him to a baby gym program. The class was fun, but there was no time to linger afterward and talk to other mothers.

So she came up with the concept for Xanadu: a bright, homey complex of large sunny rooms with couches, rugs and plenty of high-quality educational toys, where kids can play safely and parents can talk. There are snacks available, a special quiet room for nursing mothers, classes for parents and tots, parenting classes and a limited amount of baby-sitting for parents who want to go do a few errands. Every day, Xanadu orders takeout for lunch, so parents who want to stay through midday can have a salad or pizza.

To hang out at Xanadu, parents pay membership fees that can be as little as \$109 a year for one visit a month and discounts on classes or as much as \$649

a year for unlimited visits, unlimited classes and discounts on baby-sitting. It's open weekdays and Saturdays.

"I tried to focus on the parents as much as the kids," said Mason-Mann. "That's why we have couches instead of benches. It's really as much about the parents as the kids."

It's also why she picked the name Xanadu: Parents would understand the link to a mythic place of "escape and euphoria," she said.

But at first, Mason-Mann said, bankers didn't grasp what she was up to. "I talked to a lot of older men in the banking industry who had no idea what I was talking about," Mason-Mann said. "I would talk for about 20 minutes, and then they would say, 'OK, so when you open your day care...'"

Mason-Mann believes there is a widespread need for this service and hopes to franchise it.

Jen Singer, a Kinnelon, N.J., mom and creator of [www.MommaSaid.net](http://www.MommaSaid.net), a Web site for stay-at-home moms, said she knows a lot of moms "who are at Starbucks at 10 in the morning" with their babies in tow, getting "the evil eye" from customers who don't want to be disturbed.

"People use the playground as a place to get together, but what do you do in the dead of winter?" she asked.

Tina B. Tessina, a Southern California psychotherapist, called the Xanadu concept "brilliant" and said, if it is franchised, she expects it to take off just as the all-women workout centers, Curves, have.

"I urge all my single moms and mar-

ried moms to get connected to other moms," said Tessina, who is the author of "How to be a Couple and Still Be Free" (New Page Books, \$13.99). "New moms need support, and they need help from other moms who are more experienced and know what's going on and from moms who are going through the same thing."

Often young moms find that their friends are working or don't have kids or their relatives are faraway, Tessina said. "People don't get connected through the old traditional pathways. They need places that are easy and convenient." Xanadu offers "an urban-friendly way to do this. It's the way we live now," said Tessina.

Patty Dilko, an assistant professor of early childhood education at Cananda College in Redwood City, Calif., said society pays a lot of lip service to the family but doesn't really provide much support.

She said Xanadu sounds like the kind of place that would provide that support. "Hey, it's way better than going to McDonald's, which is indoor and safe, but — yuck," said Dilko.

While the cost of belonging to Xanadu can be significant, McNulty, who has the premier \$649 membership, said it has been well worth it.

"Lucy really loves it, but I'm surprised by how much I enjoy it and my husband does," said McNulty. "It's definitely exceeded my expectations. I made friends, and I have a little stack of [phone] numbers now."

"It's so nice to hang out with other adults."



Cloe Poisson / The Hartford Courant

**A stately pleasure-dome:** Ming-Mei Wolfe, 2, plays in a cloth tunnel at Xanadu Family Center while Laura Olson, a mom, chats on the couch.