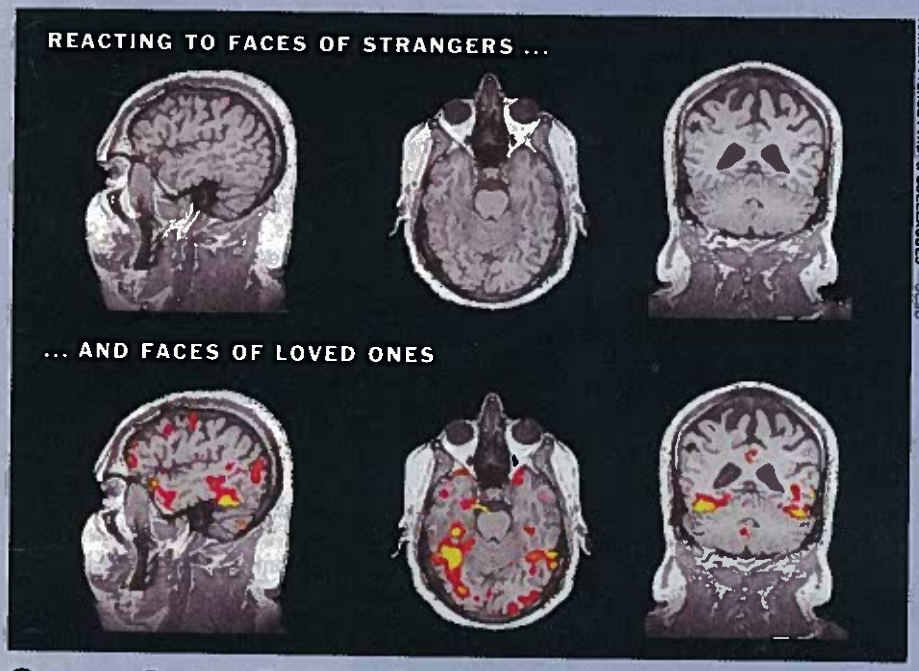
FOR PARENTS

is autistic? And what should you do if he or she is?



KAREN PIERCE PH.D. & COLLEAGUES—UCSD

Snapshots from the Autistic Brain

Neuroimaging studies confirm what scientists long suspected: autistic brains don't react to facial cues the way normal brains do. But in one regard the conventional wisdom was wrong. In a breakthrough study, Karen Pierce at the University of California at San Diego has shown that when faces of strangers are replaced by faces of loved ones, the autistic brain lights up like an explosion of Roman candles.

WHERE TO START

■ **GET AN EVALUATION:** Take your child to a developmental pediatrician with expertise in autism or Asperger syndrome. The pediatrician will evaluate your child with a team of specialists (speech therapists, occupational therapists, behavior therapists) to determine the areas in which your child needs help.

■ **EARLY INTERVENTION:** Every state is mandated to provide a free evaluation and early-intervention services for children. To find out whom to contact in your state, consult the National Information Center for Children and Youth with Disabilities (funded by the Department of Education) at *nichcy.org/index.html*. Ask about support groups in your area.

HOW TO TREAT IT

There is no cure for autism, but there are many treatments that can make a difference:

■ **SPEECH THERAPY:** Can help overcome communication and language barriers

■ **OCCUPATIONAL THERAPY:** Helps with sensory integration and motor skills

■ **BEHAVIORAL THERAPY:** Improves cognitive skills and reduces inappropriate behavior

■ **EDUCATIONAL THERAPY:** A highly structured approach works best

■ **MEDICATION:** Can reduce some symptoms

■ **SPECIAL DIETS:** Eliminating certain food groups, such as dairy, helps some children

HELPFUL WEBSITES

ONLINE ASPERGER SYNDROME INFORMATION AND SUPPORT
www.aspergersyndrome.org

AUTISM SOCIETY OF AMERICA
autism-society.org

FAMILIES FOR EARLY AUTISM TREATMENT *www.feat.org*

AUTISM RESOURCES *autism-info.com*

YALE CHILD STUDY CENTER
info.med.yale.edu/childstdy/autism

Network: Other parents can be great sources in finding the right treatments

VACCINES

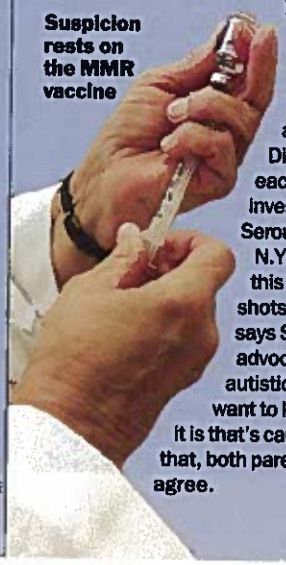
Are the Shots Safe?

Ask the parents of autistic children whether they believe childhood vaccines can cause autism, and the answer will probably be yes. They have heard of too many cases of babies who were perfectly normal until they got their measles, mumps and rubella (MMR) shot and then, within weeks—if not days—started throwing tantrums, losing language skills and generally tuning out.

Ask doctors the same question, and they are likely to cite the panel of experts convened by the Institute of Medicine last year. They studied the evidence but found no explanation for how vaccines might possibly cause autism. Included in the review were studies that showed no significant difference in the incidence of autism disorders before and after MMR immunization became routine in 1988 in Britain. "We bent over backward to look for the biological mechanisms that would support a link," says the panel's chairwoman, Dr. Marie McCormick of the Harvard School of Public Health.

But failing to prove that something can happen is not the same as proving it doesn't, and the issue is still a matter of furious debate. The only scientific evidence against childhood vaccines comes from Dr. Andrew Wakefield, formerly at the Royal Free Hospital in London. His theory is that autism stems from a severe immune reaction to something in the vaccine. In February he published a paper showing that immunized children with autism and bowel disorders have higher levels of measles particles in their intestinal tissue than normal children do. The evidence is not entirely persuasive, however; measles particles in the tissues do not necessarily mean that the virus—or the vaccine—causes autism.

What about all the children whose symptoms appeared shortly after their MMR? The association may be purely coincidental. The shots are given at 15 months, which is when behavior and speech patterns in babies usually become sufficiently pronounced for parents to start noticing that something is wrong. Most of the evidence suggests that autism is primarily a genetic disorder. It may be that some symptoms appear immediately after birth but are too subtle to be spotted in the first year or so of life.



Suspicion rests on the MMR vaccine

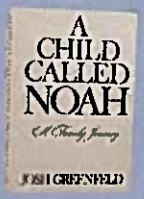
AP

To get more definitive answers, the National Institutes of Health and the Centers for Disease Control have each launched their own investigations. Karyn Seroussi of Poughkeepsie, N.Y., for one, supports this research. "If it's the shots, I want to know," says Seroussi, an autism advocate and parent of an autistic son. "If it's not, I want to know what the heck it is that's causing autism." On that, both parents and doctors can agree.

—*By Alice Park*

FIRST PERSON ■ KARL TARO GREENFELD

My Brother



My autistic brother Noah and I once played together. He was two, and I was a year older. We wrestled, and I tickled him. He responded in a high-pitched giggle, halfway between a baby's gurgle and a child's laughter. I can't remember ever playing with him again. Noah stayed forever a baby, profoundly retarded, always dependent, never very communicative. And my role changed, much too early, from playmate to steward. There was barely any sibling rivalry. There were no battles to be fought. He would always be the center of attention.

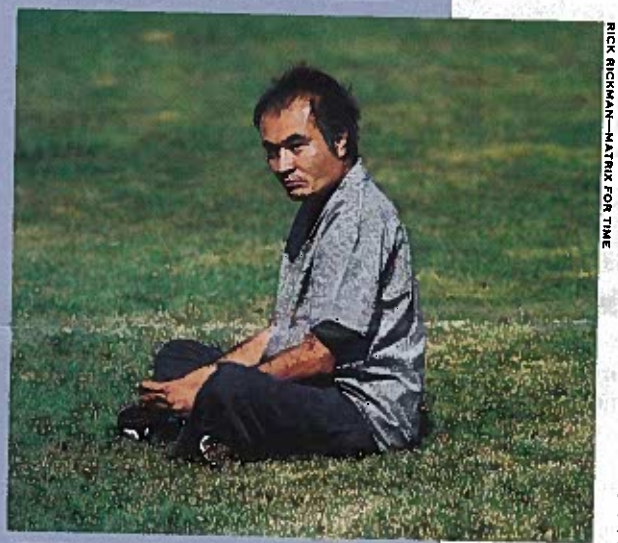
I was treated as a sort of supporting player. Because my father had written a trilogy of books about our family with Noah as the title character (starting with *A Child Called Noah;* 1972), I would often be asked what it was like having an autistic brother. I never figured out how to respond. The answer I always gave—that I had never known any other life or any other brother—seemed cryptic and somehow unsatisfactory.

But that remains the only answer I can give. Noah, who can't speak, dress or go to the bathroom completely unassisted, will always be the center of our family. He never earned that role; his needs dictated it. I wasn't consciously resentful of this as a child. There was no more reason to be angry about this than there was about the rigid laws of basic arithmetic.

I accepted the fact that Noah and his problems could fill a battleship of parental duty and obligation, leaving my mother and father too spent to worry about the more banal problems of their normal son. But at some point in my early teens, in the confusing years of adolescence, I stopped having friends over. Noah's condition dictated what we ate and when we slept and to a great degree how we lived. We never had fancy furniture because he chewed on the couch cushions and spit on the carpets. He would pull apart anything more complicated than a pencil. I was ashamed of our home and family. Already marked as different by virtue of being Asian American in a predominantly white community, I came to see Noah as an additional stigmatizing mark.

My father used to say every family has a skeleton in its closet. Only ours was out in the open. I don't even remember if I talked about Noah in school. My friends knew about him, but after the first few questions, there wasn't much to say. Noah didn't change. Autism is a condition, I knew from close up, for which there are no miraculous cures. So he always stayed Noah. This kid who shared the same black hair and brown eyes as I had but couldn't talk and wanted to be left alone. So what was there to say about Noah? He was my brother who was never going to grow up.

Noah is 35 now and has been living in institutions since he was 18. My parents visit him every weekend at the Fairview Developmental Center in Costa Mesa, California. I go whenever I am in town. (Currently I live in Hong Kong.) We bring Noah his favorite foods: sushi, fresh fruit and Japanese crackers and take him for a walk or a ride. Sometimes



RICK RICKMAN—MATRIX FOR TIME

A MAN CALLED NOAH: Now 35, he has been institutionalized for 17 years

he lashes out at me. Spitting. Scratching. Pulling hair. But he knows me; I can tell by the wary squint he gives me. We're brothers, after all.

My parents are now in their 70s. My father underwent open-heart surgery a few years ago. Eventually, the responsibility for Noah will fall solely upon me. I imagine I may have to move my own family back to California to visit him every weekend, so that those caring for him will know that despite Noah's temper tantrums and violent outbursts, he is loved; he is a brother and part of a family. He is still the center of my life. My travels, from Los Angeles to New York City to Paris to Tokyo to Hong Kong, will always bring me back to him. I don't know any other life. I have no other brother. ■

Greenfeld is the editor of TIME ASIA

tions projecting to and from the cerebral cortex and other areas of the brain, including the cerebellum. Perhaps, Courchesne speculates, it is the signal overload caused by this proliferation of connections that injures the Purkinje cells and ultimately kills them. "So now," says Courchesne, "a very interesting question is, What's driving this abnormal brain growth? If we could understand that, then we might be able to slow or stop it."

A proliferation of connections between billions of neurons occurs in all children, of course. A child's brain, unlike a computer, does not come into the world with its circuitry hard-wired. It must set up its circuits in response to a sequence of experiences and then solder them together through repeated neurological activity. So if Courchesne is right, what leads to autism may be an otherwise normal process that switches on too early or too strongly and shuts off too late—and that process would be controlled by genes.

Currently Courchesne and his colleagues are looking very closely at specific genes that might be involved. Of particular interest are the genes encoding four brain-growth regulators that have been found in newborns who go on to develop mental retardation or autism. Among these compounds, as National Institutes of Health researcher Dr. Karin Nelson and her colleagues reported last year, is a potent molecule known as vasoactive intestinal peptide. VIP plays a role not only in brain development but in the immune system and gastrointestinal tract as well, a hint that other disorders that so frequently accompany autism may not be coincidental.

The idea that there might be early biomarkers for autism has intrigued many researchers, and the reason is simple. If one could identify infants at high risk, then it might become possible to monitor the neurological changes that presage the onset of behavioral symptoms, and someday perhaps even intervene in the process. "Right now," notes Michael Merzenich, a neuroscientist at the University of California, San Francisco, "we study autism after the catastrophe occurs, and then we see this bewildering array of things that these kids can't do. What we need to know is how it all happened."

The genes that set the stage for autistic disorders could derail developing brains in a number of ways. They could encode harmful mutations like those responsible for single-gene disorders—cystic fibrosis, for instance, or Huntington's disease. They could equally well be garden-variety variants of normal genes that cause problems only when they combine with certain other genes. Or they could be genes that set up vulnerabilities to any number of stresses encountered by a child.

A popular but still unsubstantiated theory blames autism on the MMR (measles, mumps and rubella) vaccine, which is typically given to children at around 15 months (*see box*). But there are many other conceivable culprits. Researchers at the University of California at Davis have just launched a major epidemiological study that will test the tissues of both autistic and nonautistic children for residues of not only mercury but also PCBs, benzene and other heavy metals. The premise is that some children may be genetically more susceptible than others to damage by these agents, and so the study will also measure a number of other genetic variables, like how well these children metabolize cholesterol and other lipids.

Drugs taken by some pregnant women are also coming under scrutiny. At the University of Rochester, embryologist Patricia Rodier and her colleagues are exploring how certain teratogens (substances that cause birth defects) could lead to autism. They are focusing on the teratogens' impact on a gene called HOXA1, which is supposed to flick on very briefly in the first trimester of pregnancy and remain silent ever after. Embryonic mice in which the rodent equivalent of this gene has been knocked out go on to develop brainstems that are missing an entire layer of cells.

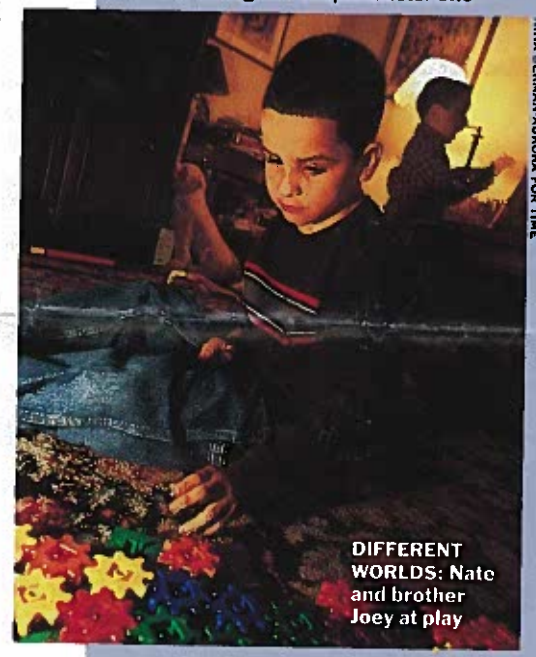
In the end, it is not merely possible but likely that scientists will discover multiple routes—some rare, some common; some purely genetic, some not—that lead to similar end points. And when they do, new ideas for how to prevent or correct autism may quickly materialize. A decade from now, there will almost certainly be more effective forms of therapeutic intervention, perhaps even antiautism drugs. "Genes," as the University of Chicago's Cook observes, "give you targets, and we're pretty good at designing drugs if we know the targets."

FIRST PERSON ■ AMY LENNARD GOEHNER

My Son

I didn't know the world that my friends with normal—or, as we call them, typically developing—kids live in until recently. Two and a half years ago, my husband and I adopted our second child, Joey. And as he has grown to be a toddler, every milestone he has reached has been bittersweet—a celebration but also a painful reminder of all the milestones our 8-year-old son Nate has never reached.

Before Joey could talk, he pointed—as if to say, "Hey, Mom, look at that dog over there"—the way kids do to engage you. I flashed back to the evaluation forms we filled out for Nate when we were taking him to specialists. One question that appeared on every form was "Does your child point?" It's a major developmental step, a gesture that communicates a child's desire to share something outside himself. Nate never pointed.



NINA BERMAN-AURORA FOR TIME

DIFFERENT WORLDS: Nate and brother Joey at play

When Nate was 2 and not talking, we took him to a big New York City hospital to get him evaluated. The neurologist gave us his diagnosis almost apologetically, in a very quiet voice. I remember just two words: "Maybe autistic."

When I stopped crying, I went to my office and called everyone I had ever met who was in any way connected to the world of special-needs kids. We made a lot of mistakes before finding the perfect match for Nate (and us)—a wonderful speech therapist whom we later dubbed our captain. When she met Nate, he was nonverbal and running around her office like a self-propelled buzz saw. She looked at us calmly and said, "Let's get busy. We've got work to do."

We've been working ever since. In addition to continual speech, behavior and occupational therapy, we have dabbled in what one of our doctors called "the flavor of the week"—vitamins and supplements and other "can't miss" cures. We shelled out a small fortune for every must-have tool that Lori, Nate's occupational therapist, mentioned even casually, including weighted vests (to help "ground" Nate) and special CDs (to help desensitize him to loud sounds). "Every time Lori opens her mouth, it costs me a hundred bucks," my husband once said.

Recently I read Joey a picture book that contained illustrations of fruit. Joey pretended to pick the fruit off the page and eat it, offering me a bite. Again I flashed back to those evaluation forms: "Does your child engage in pretend/imaginative play?" Nate's idea of play is to drop sticks and small stones into a drain at the playground. He could do this for hours if we let him. Last week Joey took a long noodle from his bowl of soup, dragged it across the table and said, "Look, it's a train. There's the freight car." Then Nate took a noodle from his soup. He tossed it onto the ceiling.

Yet maybe because I entered motherhood through the special-needs world, I somehow feel more a part of it than I do the "normal" one. The challenges in this world are greater, but the accomplishments—those firsts—are that much sweeter.

The other day I heard Joey singing a song about trains, and I realized that I couldn't remember the first time I heard my second son sing. I just took it for granted. With Nate, I never take anything for granted.

When Nate was 6, I was invited to hear his class put on a concert. I had no idea what to expect, as Nate doesn't sing. What he does do is make loud, repetitive noises, occasionally while rocking back and forth. But I went anyway. And when the music teacher approached Nate and began to sing a song Nate loved to listen to, Nate looked down, stared at his hands and very quietly chimed in, "A ram sam sam, a ram sam, gooly, gooly, gooly ... " The other moms rushed to hand me tissues as tears streamed down my face. I was listening to Nate sing. For the first time. ■

Goehner is head arts reporter at TIME

Paradoxically, the very thing that is so terrible about autistic disorders—that they affect the very young—also suggests reason for hope. Since the neural connections of a child's brain are established through experience, well-targeted mental exercises have the potential to make a difference. One of the big unanswered questions, in fact, is why 25% of children with seemingly full-blown autism benefit enormously from intensive speech- and social-skills therapy—and why the other 75% do not. Is it because the brains of the latter are irreversibly damaged, wonders Geraldine Dawson, director of the University of Washington's autism center, or is it because the fundamental problem is not being adequately addressed?

The more scientists ponder such questions, the more it seems they are holding pieces of a puzzle that resemble the interlocking segments of Tommy Barrett's Transformer toys. Put the pieces together one way, and you end up with a normal child. Put them together another way, and you end up with a child with autism. And as one watches Tommy's fingers rhythmically turning a train into a robot, a robot into a train, an unbidden thought occurs. Could it be that some dexterous sleight of hand could coax even profoundly autistic brains back on track? Could it be that some kid who's mesmerized by the process of transformation will mature into a scientist who figures out the trick? —***With reporting by Amy Bonesteel/Atlanta***

FIRST PERSON ■ TEMPLE GRANDIN

Myself

I was 2½ years old when I began to show symptoms of autism: not talking, repetitious behavior and tantrums. Not being able to communicate in words was a great frustration, so I screamed. Loud, high-pitched noises hurt my ears like a dentist's drill hitting a nerve. I would shut out the hurtful stimuli by rocking or staring at sand dribbling through my fingers.

JAY DICKMAN FOR TIME

COWGIRL: She found fame and success designing feed pens

As a child, I was like an animal with no instincts to guide me. I was always observing, trying to work out the best ways to behave, yet I never fit in. When other students swooned over the Beatles, I called their reaction an ISP—interesting sociological phenomenon. I wanted to participate but did not know how. I had a few friends who were interested in the same things I was, such as skiing and riding horses. But friendship always revolved around what I did rather than who I was.

Even today personal relationships are something I don't really understand. I still consider sex to be the biggest, most important "sin of the system," to use my old high school term. From reading books and talking to people at conventions, I have learned that autistic people who adapt most successfully in personal relationships either choose celibacy or marry someone with similar disabilities.

Early education and speech therapy pulled me out of the autistic world. Like many autistics, I think in pictures. My artistic abilities became evident when I was in first and second grade, and they were encouraged. I had a good eye for color and painted watercolors of the beach.

But words are like a foreign language to me. I translate them into full-color movies, complete with sound, which run like a videotape in my head. When I was a child, I believed that everybody thought in pictures. Not until I went to college did I realize that some people are completely verbal and think only in words. On one of my earliest jobs, I thought the other engineer was stupid because he could not "see" his mistakes on his drawings. Now I understand his problem was a lack of visual thinking and not stupidity.

Autistics have trouble learning things that cannot be thought about in pictures. The easiest words for an autistic child to learn are nouns because they relate directly to pictures. Spatial words such as *over* and *under* had no meaning for me until I had a visual image to fix them in my memory. Even now, when I hear the word under by itself, I automatically picture myself getting under the cafeteria tables at school during an air-raid drill, a common occurrence on the East Coast in the early 1950s.

Teachers who work with autistic children need to understand associative thought patterns. But visual thinking is more than just associations. Concepts can also be formed visually. When I was little, I had to figure out that small dogs were not cats. After looking at both large and small dogs, I realized that they all had the same nose. This was a common visual feature of all the dogs but none of the cats.

I credit my visualization abilities with helping me understand the animals I work with. One of my early livestock design projects was to create a dip-vat and cattle-handling facility for a feed yard in Arizona. A dip vat is a long, narrow, 2-m-deep swimming pool through which cattle move in single file. It is filled with pesticide to rid the animals of ticks, lice and other external parasites. In 1978 dip-vat designs were very poor. The animals often panicked because they were forced into the vat down a steep, slick decline. They would refuse to jump into the vat and would sometimes flip over backward and drown.

The first thing I did when I arrived at the feedlot was put myself inside a cow's head and see with its eyes. Because their eyes are on the sides of their head, cattle have wide-angle vision. Those cattle must have felt as if they were being forced to jump down an airplane escape slide into the ocean.

One of my first steps was to convert the ramp from steel to concrete. If I had a calf's body and hooves, I would be very scared to step on a slippery metal ramp. The final design had a concrete ramp at a 25° downward angle. Deep grooves in the concrete provided secure footing. The ramp appeared to enter the water gradually, but in reality it abruptly dropped away below the water's surface. The animals could not see the drop-off because the dip chemicals colored the water. When they stepped out over the water, they quietly fell in because their center of gravity had passed the point of no return.

Owners and managers of feedlots sometimes have a hard time comprehending that if devices such as dip vats and restraint chutes are properly designed, cattle will voluntarily enter them. Because I think in pictures, I assume cattle do too. I can imagine the sensations the animals feel. Today half the cattle in the U.S. are handled in equipment I have designed. ■

Grandin is an assistant professor of animal sciences at Colorado State University