

# Autism

The prevalence of this confounding disorder has reached frightening proportions, changing medicine, politics, parenting—and childhood itself. *Child* traces the ripples throughout our society.

By Tracy Mayor



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argaret MacNeil has to be one of the few mothers in the history of parenthood who was happy her baby had colic. Cormac screamed that unmistakable colic scream for his first three months. But as awful as it was, MacNeil took comfort in her firstborn's daily crying jags. It meant just one thing to her: He didn't have autism, at least not at 3 months. So far, so good.

MacNeil knows that babies with autism can be unusually easy infants, docile and rarely fussy. The 42-year-old Princeton, NJ, mom knows many other things about autism, as well, because her family has a history of the disorder, which covers a spectrum of neurodevelopmental problems characterized by repetitive, often obsessive behaviors and impairments in verbal and social skills. Her nephew, who's now a teenager, is autistic. One of her cousins has a similar set of symptoms, and looking back, the family sees now that an uncle who died young was likely autistic as well. "That's three males in my mother's family," MacNeil says, anxiety etched in her voice. "That feels like a lot to me."

The fear of autism may weigh more heavily on MacNeil than on most parents—research shows that autism runs in families—but she's not alone in her worry, not by a long shot.

The Centers for Disease Control and Prevention (CDC) in Atlanta estimates that between one in 500 and one in 166 children in America has autism. That's 10 times the number that studies counted during the late 1980s and early '90s, although the figures, like so much of the public discourse on autism, are tinged with controversy. At its most severe, autism can render kids nonverbal, emotionally unreachable, and sometimes self-abusive. On the other end of the spectrum are people with Asperger's syndrome—unusually intelligent and quick learners who nevertheless have trouble with social interactions and reading others' emotions.

Since the 1940s, when Leo Kanner, M.D., working at what is now called Johns Hopkins Children's Center in Baltimore first used the phrase "early infantile autism," a diagnosis of autism has been a bombshell for devastated parents who struggled, often in isolation, to get care and treatment for their children. Now, as the numbers climb for this confounding disorder, which typically manifests itself before the tender age of 3, autism's effects are rippling out into the neighborhood, the classroom, the doctor's office, and even the U.S. Congress, as the nation begins to grapple with the challenge before it. "The 'terrible twos' have been replaced by something that really is terrible," says Arthur Caplan, Ph.D., chair of the department of medical ethics at the University of Pennsylvania School of Medicine in Philadelphia. "Autism is leaving parents nervous in ways we haven't seen since the polio epidemic."

**Just as polio was as much a part of growing up in the 1950s as Hula-Hoops and drive-in movies, autism is becoming inextricably woven into the lives of young families today.**

### **A Disorder That's Defining an Era**

**A**utism isn't contagious, and parents' concerns in no way approach the very public hysteria of the polio years. Yet as polio did in the first half of the 20th century, before its cause and cure were discovered, autism today strikes infants and young children seemingly without reason or medical explanation. That random vulnerability can make parents feel hopeless, Dr. Caplan says: "Autism is increasing, and we don't know why."

And just as polio was as much a part of growing up in the 1950s as Hula-Hoops and drive-in movies, autism is becoming inextricably woven into the lives of young children and their

## A Cause and a Cure

Polio had Jonas Salk, who developed the vaccine that brought the disease to its knees. AIDS is still waiting for its Salk, but at least it had the 1990s, which saw huge leaps in medical care to prolong and improve lives. When will autism's turn come? Hundreds of scientists are at work trying to find a cause or a cure—the hope is, both. Here, an overview:

■ **Centers of Excellence for Autism and Developmental Disabilities Research and Epidemiology (CADDRE)** In the CADDRE program, overseen by the Centers for Disease Control and Prevention in Atlanta, epidemiologic research is being done on some 2,000 children and their families to identify genetic, environmental, socio-demographic, and other factors that make it more likely that a child will have autism spectrum disorder (ASD).

■ **Columbia University** A controversial study at Columbia, in New York City, suggests that genes involved in the immune system might make some people and not others react to mercury. Researchers gave the mercury-based vaccine preservative thimerosal to three strains of newborn mice in amounts comparable to what children got in vaccines and in the same manner. Two strains showed no ill effects, but the third, a strain sensitive to autoimmune disease, developed brain and behavioral abnormalities.

■ **The Johns Hopkins School of Medicine** A team of neurologists at the medical school, in Baltimore, have found that some autistic people show evidence of inflammation in the brain. The findings suggest the brain's immune response is involved in autism, though it's not yet clear how.

■ **National Alliance for Autism Research (NAAR) Autism Genome Project** At NAAR, in Princeton, NJ, and four of the National Institutes of Health, 170 researchers are studying 1,500 families of children with ASD to build a map of the "genomic neighborhoods" where the genes believed to be involved in autism are located and, they hope, find a cause or causes.

■ **University of California** Could toxins cause autism by altering in-utero the ability to process sound? Neuroscientists at UC San Francisco theorize that autism might arise from an inability to distinguish language from excess "noise" in the brain. A colleague at the M.I.N.D. Institute at UC Davis found that PCBs could alter parts of rats' brains that decode sounds into meaningful hearing.

families in this first decade of the new century. Statistically and anecdotally, parents today are more likely than at any time in history to know, or have, a child with autism. Christina Adams, author of *A Real Boy: A True Story of Autism, Early Intervention and Recovery*, knows 14 children in her Southern California neighborhood with the disorder. Peter Bell, CEO of the national research and advocacy group Cure Autism Now and father of a 12-year-old boy with autism, notes, "It's very rare that you meet someone who doesn't know a family that's affected. I meet strangers on planes who say they have a nephew, or a friend, or a work colleague with a child who is autistic."

The disorder is more out in the open in part because it's been pushed there by parents and autism advocates who insist that others acknowledge the overwhelming realities these families face. At the same time, it's arising as a broader cultural force. Open the sports page or flip on the television to see football star Doug Flutie talking about his autistic son, Doug Jr., and the charitable foundation set up in his name. Browse the local bookstores to find not one but two award-winning recent bestsellers with autistic characters, Mark Haddon's *The Curious Incident of the Dog in the Night-Time* and Jennifer Choldenko's *Al Capone Does My Shirts*. Witness the standing-room-only crowd that attends the announcement in Manhattan of a new private school, the Rebecca School, for children with autism and other neurodevelopmental disorders. Breeze by the newsstand to see autism featured on the covers of *Newsweek* and *Rolling Stone*.

This summer the new book *Evidence of Harm* by journalist David Kirby, a *Rolling Stone* article by Robert F. Kennedy Jr. titled "Deadly Immunity," and some well-publicized Congressional drum-beating by Florida Republican Dave Weldon, M.D., brought the disorder even further into the limelight by reopening the contentious debate over whether thimerosal, a mercury-based preservative used in some vaccines in the United States until 2003 (and still present in some pediatric flu shots), might cause autism. Some parents, who say their babies and toddlers went from normally developing to unreachably withdrawn within days or even hours of receiving a vaccine, have long said yes. But multiple epidemiologic studies have failed to support a connection. As boldfaced names in high places took the thimerosal theory mainstream, parents who'd dismissed the connection as anecdotal happenstance started to have misgivings. In response, three important public health agencies—the CDC, the Food and Drug Administration (FDA), and the National Institute of Child Health and Human Development—held a joint news conference in late July to reaffirm that childhood vaccines save lives and that no link to autism in children has ever been proven.

## Parenthood in the Age of Autism

It's no wonder that new parents like Ellie Berkowitz Handler, 32, of Hermosa Beach, CA, feel unnerved. Handler, who is working on a Ph.D. in art history while staying home with her 1-year-old son, Hayden, likes to think she knows a thing or two about distinguishing between medical science and unfounded rumors—her parents are doctors. Her father, David Berkowitz, M.D., is a gastroenterologist, and her mother, Carol Berkowitz, M.D., is a pediatrician and immediate past president of the American Academy of Pediatrics (AAP). In July *The New York Times* printed a letter from Hayden's grandmother plainly stating the AAP's position that "there is no link between exposure to thimerosal-containing vaccines and autism."

Handler and her husband had Hayden vaccinated on schedule, but she knows parents in her own neighborhood who are not following suit, one of whom passed along Kennedy's article for her to read this summer. "That woman didn't vaccinate, and there are others too," she says. "I find myself questioning my decisions, and here I am with my whole family in the medical field. A little knowledge can make you a little crazy."

With no definitive cause or cure, autism researchers are casting a wide net (see "A Cause and a Cure" at left)—looking at genetics, environmental triggers, immune-system abnormalities, difficulty during birth, early inflammation or trauma to the brain, or some combination of those elements. That in itself adds to the anxiety. With the scope of research so broad, nearly every aspect of childhood becomes suspect to autism-aware parents like Handler and MacNeil.

MacNeil worries about pitocin and about the pain medication she submitted to after 26 hours of unproductive labor, both of which have been studied in connection with, but never conclusively tied to, the increase in autism. She worries about the shot Cormac received in his first days of life for jaundice, and she worries about the two rounds of antibiotics he's been on for ear infections, two other medicines that have been suggested, but in no way proven, as possible autism triggers.

And even though the AAP and the federal public-health agencies stand by their position that childhood vaccines and the solutions they're preserved in do not cause autism, MacNeil isn't convinced. She's found a pediatrician willing to stretch out the standard schedule of childhood

immunizations, inoculating Cormac against no more than two diseases during any one office visit. (Some activists believe it's the frequency and intensity of vaccines that trigger autism in some children.) When he gets his shots, she insists on checking the vaccine's manufacturer, ingredient list, and expiration date herself to make sure there is no thimerosal in the dose before allowing Cormac to receive it. But MacNeil mostly watches and, with one eye on her son and the other on the calendar, waits for him to turn 3. "I wish I didn't depend so much on that number, but I am really waiting for 36 months to be up," she says.

### **Autism in the Doctor's Office**

**S**ome children exhibit signs of autism from birth, though often parents and caregivers recognize those signs only in hindsight. Other children appear to be developing normally, then dramatically shut down, losing language and social skills seemingly overnight. Some researchers have even examined family videos of first- and second-year birthday parties to look for unseen-at-the-time clues that children were slipping into autistic behavior.

When Adams's son was diagnosed a few months before he turned 3, she swung into action, putting Jonah (a pseudonym) on a special diet and visiting a slew of doctors, psychologists, and specialists before settling on intensive speech and behavioral therapies. Today he's a fully functioning 8-year-old enrolled in a regular education classroom with a shadow aide to assist when he needs help with a slight auditory-processing delay. In the language of autism advocates, Jonah isn't "cured" but "recovered." "He's an amazing, wonderful boy," Adams says, "living a typical child's life."

Such aggressive interventions are somewhat controversial: Not all children respond, and it's not yet clear how recovered kids fare as they enter adolescence and adulthood. (In a new wrinkle, data from patients at the Children's Hospital of Philadelphia released this summer show that some of the improvement seen in children with IQs over 70 may occur on its own as part of the natural course of autism.) What is clear is that behavioral therapies have their best chance of working the earlier autism is diagnosed. Couple that knowledge with a recent Canadian study that detected autism in infants as young as 12 months and what emerges is a newly intensified, high-stakes emphasis on early developmental milestones that's changing the traditional peek-in-the-ears, chart-the-weight childhood checkup into something else entirely.

Spurred on in part by concern over the rising number of autism diagnoses, the CDC this year launched "Learn the Signs. Act Early," a public-awareness campaign designed to emphasize that it's as important to measure a child's neurological development as it is to monitor physical milestones like sitting and walking. Pediatricians and parents are being taught to track a baby's progress in hitting such markers as developing a social smile (3 months), reacting to expressions of emotion (7 months),

**Autism concerns are helping to drive innovations in the traditional peek-in-the-ears, chart-the-weight childhood checkup.**

responding to a verbal request (1 year), and using two- to four-word phrases (2 years). It's the CDC's hope, says Marshalyn Yeargin-Allsopp, M.D., a medical epidemiologist with the CDC's National Center on Birth Defects and Developmental Disabilities, that the campaign will serve as a springboard for parents and healthcare providers to talk more openly about developmental delays.

This new focus has the potential to help many preschoolers—not just those with autism, says Nancy Wiseman, founder of First Signs, Inc., an organization focused on early identification and intervention in developmental disorders and author of the forthcoming *Could It Be Autism? A Parent's Guide to the First Signs and Next Steps*. "Learning disabilities, language delays, nonverbal learning disorders, attention deficit hyperactivity disorder, vision and hearing problems, metabolic disorders, mental retardation," she ticks off. "Any of these that we can catch in the net now can help that child."

If early identification and treatment is the silver lining of autism awareness, its darker flip side is a kind of milestone mania that can rob new parents of some of the bliss of their babies' very earliest

## A Friendship Bridge to Kids With Autism

It's a paradox: One defining characteristic of autism spectrum disorder (ASD) is social impairment. Yet most kids with ASD need and want friends, and they have a lot to offer their "neurotypical" peers, says Christina Adams, author of *A Real Boy: A True Story of Autism, Early Intervention, and Recovery*. How to bridge the divide? Adams and other parents of autistic children offer a few suggestions to keep in mind as you and your children interact with autistic kids:

■ **Bond through simple child's play.** Games like follow-the-leader or rolling a ball back and forth can be a good way to connect with children who have autism, since many enjoy simple interactive play, says Karen Siff Exkorn, author of *The Autism Sourcebook: Everything You Need to Know About Diagnosis, Treatment, Coping, and Healing*. To minimize frustration, she recommends guiding the new playmates to activities the child with autism already enjoys. "You don't want to have a situation where the typical peer says, 'Let's build a tower!' to a child with autism who has poor motor skills."

■ **Don't be afraid to ask questions.** If you or your child is feeling nervous before a playdate or group outing, it can help to inquire about special situations that might arise and how to handle them. Some ASD kids are extremely sensitive to loud noise, for example. You might ask how to calm a child if the volume level gets too high during an afternoon play session.

■ **Invite autistic peers to your children's birthday parties.** If two hours at a loud, chaotic arcade isn't their cup of tea, they or their parents can always decline. Autistic kids and their families know when they're being left out, and it hurts, says Adams.

■ **Don't give up.** Many autistic kids are capable of connecting with their peers, but not always on the first try. If your initial efforts to be friendly didn't elicit much response, "try a different day, try a different way," suggests Nancy Wiseman, founder of First Signs, Inc., specializing in young children's developmental disorders.

■ **Don't judge.** That meltdown you're witnessing at the playground could be the response of an overstimulated autistic child, and parents say hard stares from strangers only make them, and their child, feel more isolated. If you see a parent really struggling, reach out, suggests Wiseman: Ask if you can help in any way.

days and months. "The neurological stuff is always in the back of my mind," admits Handler. "My son is very social, but I am still always asking my mom, 'Is this okay? Is that okay? What do you think?'"

"There's a lot of free-floating anxiety among these young moms," says Handler's mother, Dr. Berkowitz, who notes that autism anxiety seems most prevalent in middle- and upper-class parents, perhaps because they have both the education and the time to keep up on developmental issues. Marsha Winokur, Ph.D., a psychologist with the Child Development Center at the Jewish Board of Family and Children's Services in New York City, worries about this worry. She's concerned that parents are missing the forest as they stare at one tree, then another, watching their babies for any kind of developmental delay.

"Not every developmental blip means something," says Dr. Winokur. "If there's a problem, you'll know. The trusted adults in your child's life will know—the pediatrician, the daycare, the school, the grandparents. In the meantime, you have a responsibility to relax and celebrate your child."

## Autism and Public Policy

Under the federal Individuals with Disabilities Education Act (IDEA), children with autism are entitled to a "free, appropriate public education." But as more autistic children reach school age, battle lines are starting to be drawn over what "appropriate" means, underscoring the need for society to find solutions that meet these young citizens' special needs.

Autism spectrum disorders are extremely difficult to address—effective care can include a behavioral therapist, a speech therapist, an occupational or physical therapist, a nutritionist, a developmental pediatrician, a pediatric neurologist, gastrointestinal and immune-system specialists, and supplemental programs like sensory therapy (to address over- or undersensitivity to light, sound, or touch) and training in interpersonal relationships. The expense of this array of services can be staggering. Tuition for the inaugural 2006–2007 school year at the Rebecca School is a daunting \$72,000. Many parents of autistic children are hiring lawyers to ensure that their school districts pay for the help their child needs.

But school boards say their backs are to the wall. Congress has typically paid only 15% to 18% of states' IDEA costs rather than the 40% it promised, according to the National Education Association in Washington, DC, and state school boards. With state and local education budgets slashed or flat, local school systems have a smaller pie to divide up at the precise time when more autistic children are enrolling. "That puts the school board and communities in a difficult position," says Ted Comstock, executive director of the New Hampshire School Boards Association, speaking for a state with some of the highest increases in autism cases tracked by the Department of Education. Communities are often forced to choose between scaling back services for autistic and other special-needs children and raising property taxes, a no-win choice that can turn school board meetings into "internal warfare," he says.

The Thompson School District in Colorado made national headlines this summer when it announced plans to fight a state order to cover the costs for a local family to send their autistic son to a residential facility in Boston. The price tag, initially estimated at \$150,000 annually, now looks like it will be closer to \$250,000, according to Becky Jay, president of the board of education for the district, which serves the towns of Loveland and Berthoud. "For a quarter of a million dollars, we could hire five teachers," she says.

The solution Jay and many others call for—full federal funding of IDEA—isn't likely anytime soon. But partial relief may come from another quarter in Washington. In a town where nearly no cause draws support from both sides of the aisle, a bipartisan group of legislators this spring introduced the Combating Autism Act of 2005, which could channel money to researchers, schools, and families. Sponsored by Rick Santorum (R-PA) and Christopher Dodd (D-CT) in the Senate and Mary Bono (R-CA) and Diana DeGette (D-CO) in the House, it calls for dedicating at least \$550 million over five years for research, screening, intervention, and education—a figure that advocates call woefully low but a start. The bill is currently awaiting action in committee. "Families struggling to raise a child with autism deserve our support, and they deserve answers," says Senator Dodd. "Many autistic children will require support well into their adult lives. This clearly puts our state and local governments, and our schools, in a significant financial bind."

## Autism in the Classroom

Fortunately, the economic rancor hasn't seemed to spill out into the classroom or onto the playground. Parents of autistic children like Peter Bell and educators like Rosemarie Young, immediate past president of the National Association of Elementary School Principals in

Alexandria, VA, say that playmates and classmates respond to autism's spectrum of symptoms with their own spectrum of inquisitiveness, awareness, kindness, and understanding. (See "A Friendship Bridge to Kids With Autism" on page 178 for ways to reach out yourself.) "If the principal has set the right tone for the school and the teacher has set the right tone for the classroom," says Young, "the children are very understanding and very accepting."

Each fall since Tyler Bell was in kindergarten, his dad or mom would visit his classroom, using age-appropriate language to explain what it's like to have autism. Kids would try to become experts, says Bell, and volunteer all manner of medical information. One child suggested that his father, a pharmacist, might have access to medicine that could help Tyler. Or they'd empathize—drawing parallels between Tyler's behavior and, say, their own comportment in church (a typical comparison: Tyler makes loud noises at the wrong times, and sometimes so do I). Or they'd be observant and inquisitive. "They'd ask, 'Why does Tyler like to eat crunchy things so much?'" Bell recalls.


Those outreach efforts can pay big dividends. Tyler, now 12, switched schools last year, making him the new kid at Grand View Elementary School in Manhattan Beach, CA. The student council president, Blake Range, 11, made a particular effort to include Tyler, which touched and gratified Bell, although Range says he didn't do anything heroic. "When I first met him, Tyler was a bit insecure around other kids—well, shy," he corrects himself. "So I just introduced myself to him and said if you ever need help, you can ask me." After a few weeks, Range says, Tyler opened up a bit: "He started talking a lot more around other kids and talking more to me too."

Tyler's mom had spoken to the class the first day of school, saying Tyler might wander during the middle of class, start talking at the wrong time, or jump out of line for no reason. "She said we weren't supposed to baby him, just tell him firmly to stop talking or get back in line," Range recalls. But Range and his friends found something that worked even better: math.

"Tyler really, really, really likes math," Range confides. "So when he starts to get hyper in line or something, we give him some math facts. We just go, what's 92 times 64? And then he's fine. Sometimes he spends his whole study hall just doing math facts."

**"There's going to be more and more autistic people in the world," says one 11-year-old. "It's unfair to treat them any differently than you treat your friends."**

Tyler isn't the first student at Grand View Elementary School to have autism—there are others, though none had been in Range's class before, and he suspects Tyler won't be the last. "There's going to be more and more autistic people in the world," Range observes. "It's unfair to treat them any differently than you treat your friends."

The 11-year-old's particular brand of inclusion is one adults would do well to emulate as America begins to grapple with autism as a social issue. Most people now being diagnosed with autism are young children, still in the care of their parents and covered by strictures like IDEA. What happens when these children become adults who need housing, jobs, ongoing and by all estimates staggeringly expensive specialized medical care—adults who need understanding and a fulfilling place in their communities? "Right now, autism is in the same boat as AIDS was in the 1980s. Eventually, AIDS became everyone's problem and we made a lot of advances," observes Bell. "Autism is no longer a problem that affects families. It's a problem that affects our entire society." 



Visit [www.child.com/web\\_links](http://www.child.com/web_links) to connect to the CDC's new "Act Early" primer on what to look for in a baby's social and neurological development, along with a sample letter urging legislators to support the Combating Autism Act of 2005.

**TRACY MAYOR** lives outside Boston with her husband and their two sons. She has written on a broad range of topics for *Salon*, *The Boston Globe Magazine*, and *Brain, Child*.