What Happens When They Grow Up

Teenagers and young adults are the emerging face of autism as the disorder continues to challenge science and unite determined families.

BY BARBARA KANTROWITZ AND JULIE SCELFO

CHICKEN AND POTATOES. CHICKEN and potatoes. Danny Boronat wants chicken and potatoes. He asks for it once, twice ... 10 times. In the kitchen of the family's suburban New Jersey home, Danny's mother, Loretta, chops garlic for spaghetti sauce. No chicken and potatoes, she tells Danny. We're having spaghetti. But Danny wants chicken and potatoes. Chicken and potatoes. His 12-year-old sister, Rosalinda, wanders in to remind her mother about upcoming basketball tryouts. His brother Alex, 22, grabs some tortilla chips and then leaves to check scores on ESPN. His other brother Matthew, 17, talks about an upcoming gig with his band. Danny seems not to notice any of this. "Mom," he asks in a monotone, "why can't we have chicken and potatoes?" If Danny were a toddler, his behavior would be nothing unusual. But Danny Boronat is 20 years old. "That's really what life with autism is like," says Loretta. "I have to keep laughing. Otherwise, I would cry."

Autism strikes in childhood, but as thousands of families like the Boronats have learned—and thousands more are destined to learn—autism is not simply a childhood disorder. Two decades into the surge of diagnoses that has made autism a major public health issue, a generation of teenagers and young adults is facing a new crisis: what happens next?

Danny Boronat, 20: Three days a week, he goes to a sheltered workshop to perform assembly-line tasks. At home, he helps out with family chores. The bedroom he shares with his brothers is decorated with numerous skiing medals. His father, Alex (at right), calls Danny 'my best friend.'

PHOTOGRAPHS BY ERIC OGDEN FOR NEWSWEEK

Christopher Jorwic, 17: He doesn't speak, despite therapy since childhood. His parents, Lee and Terri, who have been active in the autism movement for years, call him their 'gentle giant.' Caring for him takes extraordinary effort; they fear what will happen when they die.

As daunting as that question may be, it's just the latest in the endless chain of challenges that is life for the dedicated parents of children with autism. Twenty years ago, they banded together—largely out of desperation—to raise awareness of a once rarely diagnosed, often overlooked disease. They are united by the frustration of dealing with a condition that has no known cause and no cure. They have lobbied passionately to get better education for their kids and more money for research into autism, a neurological disorder characterized by language problems, repetitive behaviors and difficulty with social interaction. At the same time, more sophisticated epidemiology has revealed the true magnitude of the problem. Autism is now estimated to affect from one in 500 to one in 166 children—or as many as 500,000 Americans under 21, most male. That includes individuals with a wide range of abilities—from socially awkward math whizzes to teens who aren't toilet trained—but who all fit on what scientists now consider a spectrum of autism disorders.

The culmination of much of this parental activism is the Combating Autism Act, which was pushed by a collection of advocacy groups like Cure Autism Now, led by Hollywood producer Jon Shestack and his wife, Portia Iverson; Autism Speaks, started by Bob Wright, CEO and chairman of NBC Universal, and the Deirdre Imus Environmental Center for Pediatric Oncology. The bill unanimously passed the U.S. Senate in August but was blocked in the House by Texas Republican Joe Barton, chair of the House Committee on Energy and Commerce. In a September meeting, Barton told autism activists that he would continue to oppose their legislation, which earmarks $945 million for research over the next five years, because it conflicted with his own proposal to reform the National Institutes of Health. As a result, autism advocates began inundating him with faxes and phone calls and lambasting him in the press. To advance the cause of research, radio host Don Imus joined in and pressured Barton on the air, calling the congressman, among other things, "a lying, fat little skunk from Texas."

Join a Live Talk on autism, Nov. 22 at noon, ET, at **xtra.Newsweek.com**

Now that the Democrats have won the House, Barton will lose his chairmanship in January and NEWSWEEK has learned that he is attempting to pass a compromise version of the bill before then. If passed, the House bill would fund a new push for early diagnosis, which is critical to starting therapy as soon as possible. In a particular victory for parents, the legislation specifies that the research oversight committee should include at least one person with autism and a parent of a child with autism.

PHOTOGRAPH BY ERIC OGDEN FOR NEWSWEEK

Dov Shestack, 14: At a recent holiday meal, a family friend praised her fiancé's romantic proposal. Dov cried, telling his mother, 'Girls want voices.' He communicates using a letter board.

The House bill authorizes money for research into many questions, including whether environmental factors may trigger autism. One point of contention: the Senate bill mandated a specific amount of money for the NIH to research the role environmental factors might play in causing autism. But Barton resisted, and now the specificity about how much should be spent and where has been lost in the compromise version. Still, a Barton bill could come up for a vote as early as the first week in December and the legislation, says Alison Singer, the mother of a daughter with autism and an executive at the advocacy group Autism Speaks, "is probably the single most important thing that could happen besides the cure."

A win in Washington may lift their spirits, but a legislative victory won't really change much for the Boronats and others like them. Some kids have made dramatic progress after intensive physical and behavioral therapy; many others still struggle with basic activities. Often, when lower-functioning young people reach 18, their parents will establish legal guardianship to protect them. But no matter what level they've reached, many will need help for the rest of their lives. Most government-sponsored educational and therapeutic services stop at the age of 21, and there are few residential facilities and work programs geared to the needs of adults with autism. "Once they lose the education entitlement and become adults, it's like they fall off the face of the earth" as far as government services are concerned, says Lee Grossman, president and CEO of the Autism Society of America, a major national-advocacy group.

According to the Harvard School of Public Health, it can cost about $3.2 million to care for a person with autism over a lifetime. Caring for all persons with autism costs an estimated $35 billion per year, the same study says. Families with limited financial resources are particularly hard hit. Other chronic diseases like diabetes are covered by insurance. But parents of youngsters with autism "have to navigate a maze and, if they find providers, then they have to figure out how to pay for it," says Singer. Grossman's early wish for the Combating Autism Act was that it would address the dire needs of autistic adults, and he drafted 30 pages of service-related issues. But that part was never introduced because a consortium of activists working on the bill concluded, for the sake of political expediency, that the bill shouldn't try to take on too much. In this light, restraint seems especially critical now, when the Iraq war has siphoned off so much federal money. "It's like a forest fire running through science and it burns a lot of trees down," says Dan Geschwind, a UCLA neurogeneticist. However, advocacy groups vow that the moment the bill passes, government funding for adult services will become their next priority. Wright believes there is substantial congressional support for this, possibly from Sen. Hillary Clinton.

Moving through adolescence to adulthood is never easy, but autism transforms even the most routine activities into potential minefields. Recognizing the norms of teen behavior can be a Sisyphean task. Helen Motokane's daughter, Christine, 14, has Asperger's syndrome, a high-functioning form of the disorder. She struggles to fit in at her Los Angeles public school—and that means hiding parts of her true self. One secret: she loves Barbie. "She knows it's not cool to wear clothes with Barbie logos, so she tries to keep that at home," says Helen, who gently prods her daughter into developing more mature interests. "She says, 'You're trying to make me grow up, aren't

Adolescence is never easy, but autism transforms even routine activities into potential minefields.

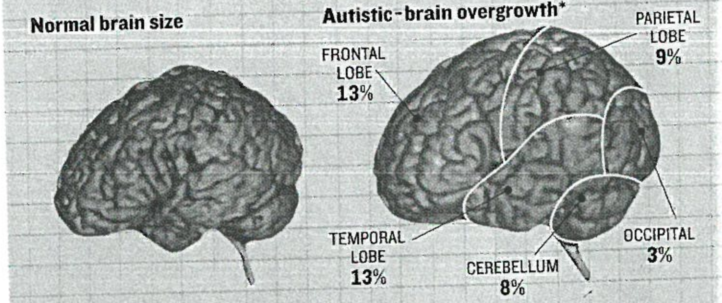
PHOTOGRAPH BY ERIC OGDEN FOR NEWSWEEK

Unlocking the Secrets of Autism

Autism is a neurological disorder that appears during the first three years of life. It affects social and communication skills in as many as 1.5 million people in the U.S. An overview:

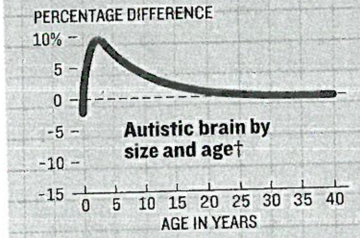
The Growing Brain

The brain of a child with autism is, on average, about 10 percent larger than a normal brain. Growth varies by region and age and has been linked to behavior.



THE DIFFERENCES: The average volume of a healthy young child's brain is about 1,180ml. An autistic brain can be closer to 1,300ml. Unlike the brain of a child with autism, that of a healthy child continues to grow until adolescence. The autistic brain can grow to its full size roughly eight to 10 years prematurely, which may influence the generation of neural circuitry and the child's behavior patterns.

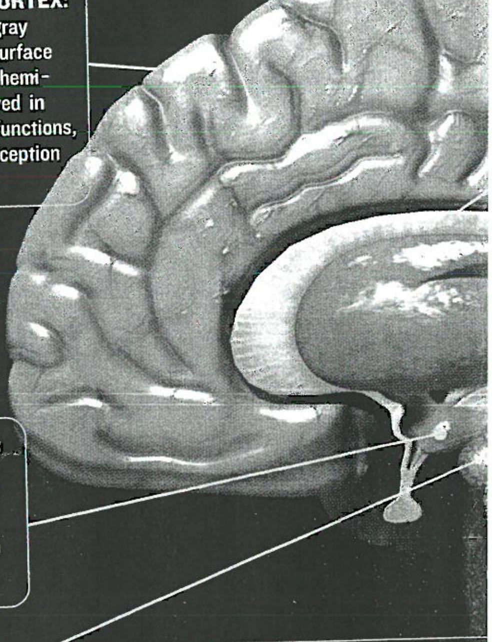
WHEN BRAIN SIZE CHANGES: At birth, the autistic brain is similar in size to a healthy child's brain. Between birth and 2 years it grows to be abnormally large, reaching its maximum size between 3 and 6 years of age.



*LOBE PERCENTAGES ARE ESTIMATES. † LINE GRAPH BASED ON 19 REPORTS.

Areas Implicated in Autism

Studies have shown that there are several parts of the brain linked to the disorder. A look at some areas affected in autism:



CEREBRAL CORTEX: A thin layer of gray matter on the surface of the cerebral hemispheres. Involved in higher mental functions, movement, perception and behavior.

AMYGDALA: Responsible for emotional states, such as aggression and fear

HIPPOCAMPUS: Plays critical role in processing new information and events

BRAIN STEM: Controls basic functions essential to survival, such as breathing and heart rate

Possible Causes

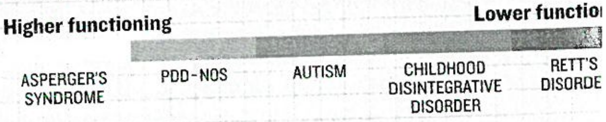
- **Genetics:** Few theories maintain that a single gene causes autism. Multiple genes, possibly ranging in number from five to 15, or gene networks, are now thought responsible.
- **Environmental factors:** Chemicals such as pesticides or PCBs, as well as infections, may play a role.
- **Gene-environment interaction:** Genetic variations—the MET gene, for instance—could increase susceptibility to environmental factors.
- **Hormone imbalance:** About four times as many boys as girls have autism, leading some experts to believe that hormone imbalances during development could play a determining who develops the dis

Warning Signs

- Does not babble or coo by 12

Autism Spectrum Disorders

A RANGE OF CONDITIONS: The disorders on the spectrum are characteri by severe impairment in certain areas of development, including social and communication skills. Autism is the best known of the group.

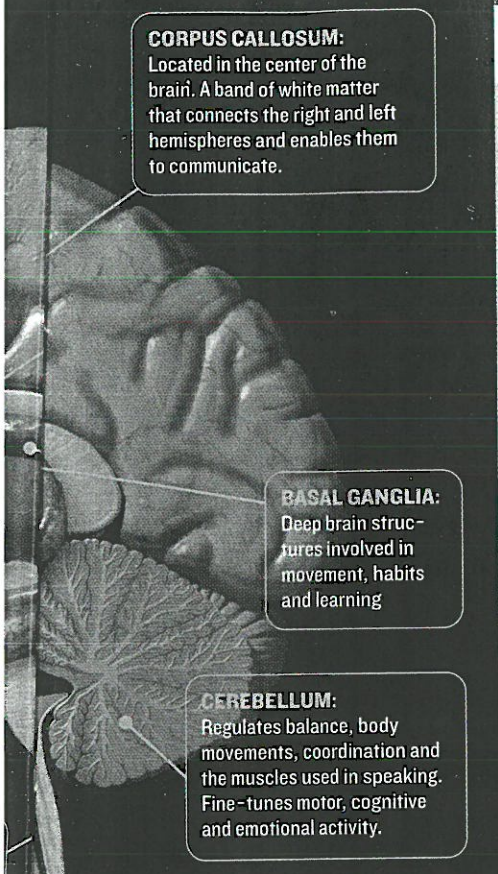


you? You want me to do all these things right away.' I go, 'No, no, no.' I reassure her that we're not trying to push her." But an hour or two later, her mother says, Christine will ask, "Is it OK if I like Disney Princess even though other kids my age don't like it?"

Keri Bowers of Thousand Oaks, Calif., says her son, Taylor Cross, 17, seems perfectly normal at first. But sometimes he'll just blurt out what he's thinking without any internal censorship. Passing a stranger on the street, he might say, "You're in a wheelchair!" "When you're socially odd, people are afraid," Bowers says. "They want to get away from you and cross to the other side of the street." Not surprisingly, Taylor had no friends at all in the public school he attends until he began to meet other teens with autism—young people his mother describes as equally "quirky."

In one way, he's not quirky at all. "He's attracted to girls," Bowers says, "but he's shy. He doesn't really know how to talk to them." A few months ago, he asked out a girl from his school who does not have autism but who had been friendly to him. Bowers had a psychologist friend shadow the couple at the movies. "Taylor only spoke about subjects he was interested in," Bowers says. "He wouldn't do a reciprocal back-and-forth conversation on topics about her." Still, when Bowers later asked if he wanted to kiss the girl, Taylor surprised his mother with his sensitivity. "He said, 'Yes, but she's very
gious and I would never do that.'"

As young people with autism appr
adulthood, some parents can't help but
the huge gaps between their child's lives
others the same age. "It's very hard, espe
ly in our competitive society where pe
strive for perfection," says Chantal Si
Kira, whose son, Jeremy, 17, can comm
cate only by pointing to letters on an alph
board. The San Diego resident hosts
Real World of Autism With Chantal" o
Autism One Radio Internet station
wrote "Adolescents on the Autism
trum" (*Penguin, 2006*). Like many yo



CORPUS CALLOSUM: Located in the center of the brain. A band of white matter that connects the right and left hemispheres and enables them to communicate.

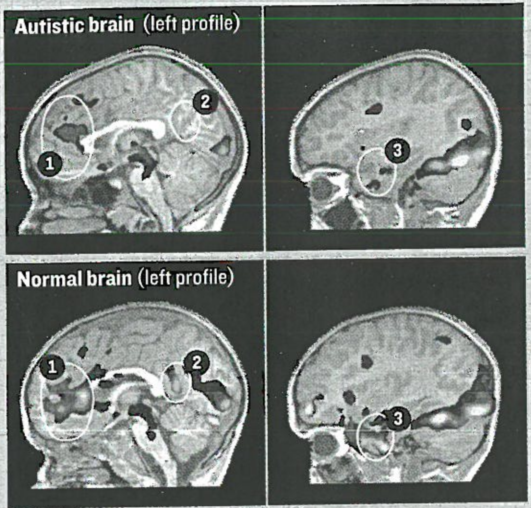
BASAL GANGLIA: Deep brain structures involved in movement, habits and learning

CEREBELLUM: Regulates balance, body movements, coordination and the muscles used in speaking. Fine-tunes motor, cognitive and emotional activity.

ILLUSTRATIONS BY KEVIN HAND AND STANFORD KAY. SOURCES: NATIONAL INSTITUTE OF MENTAL HEALTH; AUTISM SOCIETY OF AMERICA; NEWS REPORTS; ERIC COURCHESNE, KAREN PIERCE, CYNTHIA SCHUMANN, DEPARTMENT OF NEUROSCIENCES, UCSD; MARTHA HERBERT, HARVARD MEDICAL SCHOOL.

Minds at Work

The upper two scans show how the autistic brain responds when viewing pictures of an emotionally important person, such as a mother. The lower two show how a healthy brain responds. The size of the colored areas correspond to neural activity.



Autistic brain (left profile)

Normal brain (left profile)

FUNCTIONAL DIFFERENCES: ① **Medial frontal lobes.** Ascribe social and emotional meaning and interpretation. Also involved in how we fit ourselves into the world around us.

② **Posterior cingulate.** Highly active when we remember emotional events in our lives, such as a birthday party.

③ **Superior temporal gyrus.** Processes auditory stimuli. The amygdala, a structure deep within, assigns emotional significance to images and events.

- Does not gesture (point, wave, grasp) by 12 mos.
- Poor eye contact
- Delayed in learning speech
- Does not say two-word phrases on his or her own by 24 mos.
- Doesn't know how to play with toys
- Excessively lines up toys or objects
- Doesn't respond to name

Treatments

- **Learning approaches:** These strategies address language, sensory and behavioral difficulties. Among the most accepted forms of treatment is applied behavior analysis, which teaches skills (like getting dressed) in a series of simple steps. ABA also helps reduce inappropriate behavior patterns and provides regular reinforcement of appropriate behavior.
- **Biomedical and dietary approaches:** Medication is used to treat behavioral problems like aggression, not the underlying condition. The type of medication will differ based on the behavior a doctor is attempting to address. Research has also found that gluten and casein are not properly processed in the bodies of some children with autism; incomplete breakdown and excess absorption may disrupt brain functions. A gluten-free, casein-free diet is thought to address this problem. Some consider vitamins helpful. A common supplement used in autism is vitamin B, which plays a role in creating enzymes needed by the brain. Essential fatty acids have also been shown to improve behavior.

—JESSICA RAMIREZ and MARC BAIN

sters with autism, Jeremy finds new environments difficult. "If he walks into a new store," his mother says, "and there's horrendous fluorescent lighting, within 10 minutes I'll look down and he's starting to wet himself." Despite such challenges, Sicile-Kira plans to help Jeremy live on his own when he's an adult—perhaps rooming with another young person with autism.

Independent living is a major goal of many families and, with the help of therapy, thousands of youngsters who in earlier generations would have been consigned to institutions are now going to college and looking forward to a normal life with a job. But for every one who makes it, there are many more young people like Danny Boronat, who has come so far and yet still faces much uncertainty. Once unable to utter a sentence, Danny now reads at a second-grade level, competes in the Special Olympics and willingly takes on household chores like loading the dishwasher. But he also can spend hours playing with water. He picks obsessively at his cuticles, and sometimes cuts himself (his mother tries to hide any scissors in the house). He has no close friends. Next year he'll turn 21 and will no longer be eligible for the workshop where he does simple assembly-line work three days a week. After that? No one knows, not even his parents. "It's terrifying," says his mother, who started her own charity called DannysHouse to focus on adults.

A few states like California and Connecticut, newly aware of the crisis, have launched efforts to meet adult needs. But until programs are widely available, families are left to cobble together a patchwork of solutions—from informal day care to hourly caretakers to private residential programs. But these are stopgap measures. Parents worry that they will run out of money to pay for these services—and that they won't be around forever to arrange them for their children.

It's understandable that these parents would feel distraught. Many adults with autism require so much special care that it's hard to imagine anyone but a loving family member willing to provide it. "My wife and I are concerned about what's going to happen to our son when we pass on," says Lee Jorwic, whose son Christopher, 17, is unable to speak even though he's been in therapy since childhood. At 6 feet 4 inches and 290 pounds, Christopher is "our gentle giant," his father says. But because of his disabilities, even the most routine tasks require extraordinary preparations. Two years ago, for example, Christopher got an eye infection. He couldn't sit still long enough for the doctor to perform an exam so he had to go under anesthesia twice "just so the guy could look in his eye," his father says. Grossman

> 'Parents fight this all their lives, and then they don't have a place for their child after they die.'

says the Autism Society gets hundreds of calls every day from families like the Jorwics. "The most distressing, most disheartening, are from parents of older kids, parents who are at the end of life," he says. "They've been fighting this all their life, and they don't have a place for the kid after they die."

The natural successors to parents as caretakers would be siblings. Some families feel that's too much of a burden; others say that's a natural part of life in a family with autism. When one sibling has autism, the needs of so-called neurotypical children may seem to come second. Beth Eisman of Potomac, Md., recently sent her oldest daughter, Melanie, 18, off to college. Her goal for her younger daughter, Dana, 16, is more basic: independence. Dana's tantrums limited the family's participation in Melanie's school activities. "The old days were pretty bad," Eisman says. "Melanie often took the brunt of it." Now that Melanie is gone, Dana feels the loss. Eisman says Dana often goes into her sister's room and says, "I want Melanie."

Many families are sustained knowing that, by raising awareness of autism, they have already given their children the gift of a meaningful identity. "If this was 10 years ago, my daughter's classmates might say she's the one who talks to herself all the time and flaps her hands," says Roy Richard Grinker, an anthropologist at George Washington University and father of Isabel, 15. "But if you ask these kids in 2006 about Isabel, they say she's the one who plays the cello and who's smart about animals." Inspired by his daughter, Grinker explored autism in different cultures for his book "Unstrange Minds: Remapping the World of Autism" (*Basic Books, 2007*). "The more peers of the same age group understand about autism, the more likely they are to be kind, caring and integrate them into community life."

Twenty years ago, that kind of acceptance was inconceivable. Autism was considered rare and few physicians understood it or were able to help. The disorder was first identified by Leo Kanner of Johns Hopkins in 1943. About the same time a German scientist, Hans Asperger, described a less severe form of the condition. But with the as-

Dana Eisman, 16: She loves libraries and has a job at school filing books. She listens to the 'Curious George' theme song on her iPod. 'People say God gives you something because he feels you can handle it,' says her mother, Beth. 'I can handle it, but I want a cure.'

New clues and new questions in the hunt for a cause.

A Terrible Mystery

BY MARY CARMICHAEL

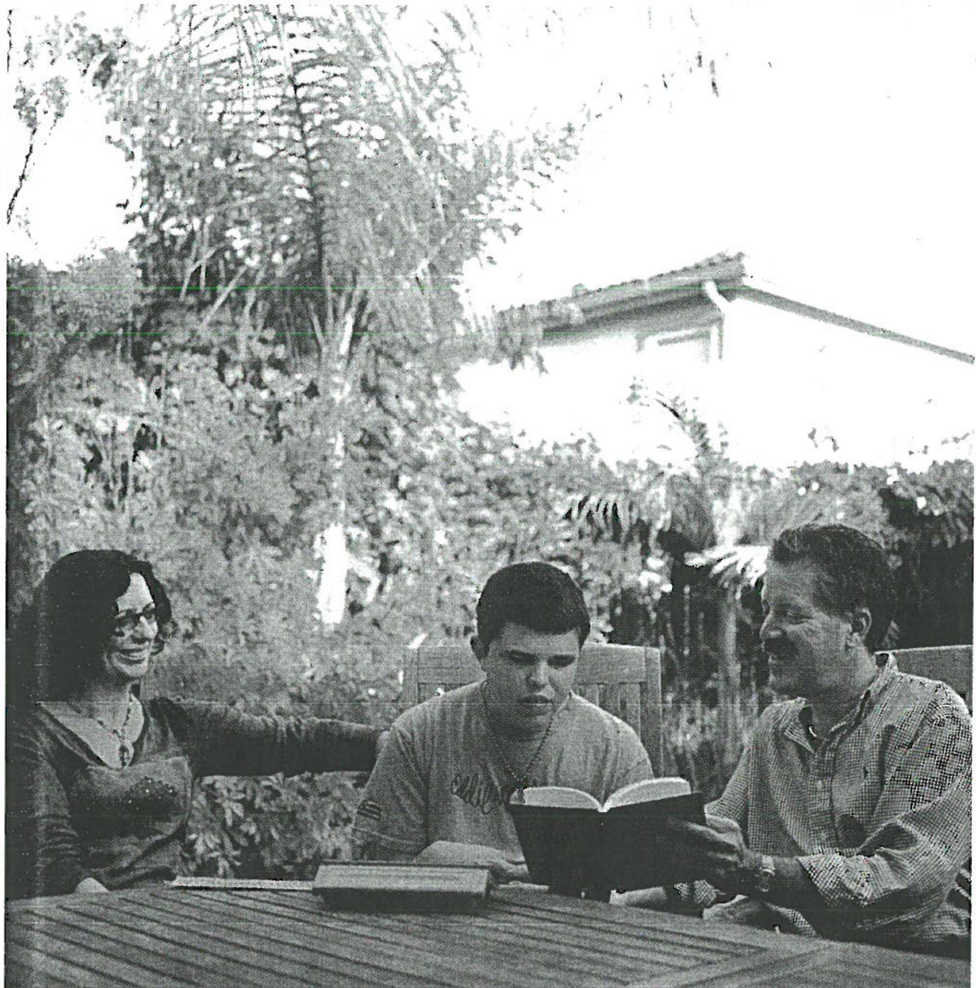
Thomas Insel spent years training as a psychiatrist in the 1970s, and in all that time he saw not one child with autism. In 1985, curiosity sent him searching; it took several phone calls to find a single patient. His only prior exposure to the disorder was a lecture in which Bruno Bettelheim "explained that it was due to evil mothers." The '70s were, he says, "an era of psychiatry that had no science."

Today's psychiatry has science—and it *is* science—and increasingly, it is offering hope for patients with autism. As director of the National Institute of Mental Health, Insel now heads an agency that funds autism research all over the nation and also conducts projects of its own. Thanks to revolutions in neuroscience and genetics, scientists are starting to unravel the shroud of mystery that has hung over autism since it was first described in 1943. But with each new discovery, more questions arise.

That includes the most fundamental question of all: what is autism? Although the basic symptoms are well defined, researchers are now trying to categorize the secondary ones, a suite so varied that Insel's colleagues have started referring to the disease as "autisms." Some children with the disorder never speak. Others "are so fluent that you can't shut them up," says Sarah Spence, a pediatric neurologist at the NIMH. About 20 percent of kids with autism hit early developmental milestones but regress around 15 to 18 months; the rest don't make it that far. What binds them all together is largely unclear.

But autism is known to be highly heritable, and last month, in what was viewed as a major breakthrough, Vanderbilt University's Pat Levitt identified the first common gene that plays a role. The MET gene helps build the brain in utero and in childhood. A faulty variant appears in 47 per-

FROM LEFT: PHOTOGRAPH BY BY ERIC OGDEN FOR NEWSWEEK, PHOTOGRAPH BY JP GREENWOOD FOR NEWSWEEK



Jeremy Sicile-Kira, 17: He attends public high school and has started a flower-selling business to raise money to buy a dog. His mother, Chantal (left), has written a book about teens on the autism spectrum. His father, Daniel (right), plays in a band with him.

cendancy of psychoanalysis in the postwar years, the predominant view was that autism was a psychological disorder caused by a lack of love from "refrigerator mothers," a term introduced by the controversial psychologist Bruno Bettelheim. In the 1970s, parents started pushing back against this theory and encouraging researchers to look for neurological causes. It wasn't until 1980 that autism became an official clinical diagnosis, separate from childhood schizophrenia or retardation. Since that time, as scientists have learned more, they have broadened the diagnosis to include a spectrum of disabilities. Now, they are re-evaluting it even further, considering the idea that there may be multiple "autisms" (sidebar).

As knowledge about autism spread in the 1990s, families began to get more accurate diagnoses for children who might in the past have been labeled mentally retarded or emotionally disturbed, and the number of cases skyrocketed. Because of the Internet and extensive networking, parents around the country found allies and became powerful and articulate advocates. Even longtime autism researchers say families have really led the way. "Beyond raising awareness," says Dr. Thomas Insel, director of the National Institute of Mental Health, "families have become the real experts on this disorder. They have to figure out how to cope with a child who becomes explosive, disruptive, who could have a meltdown at any moment. They become highly skilled at knowing what helps."

Autism has set all these families on a unique journey and, while the road ahead is still unclear, they cherish small triumphs along the way. Grinker has a Ph.D. from Harvard and, in his community, many parents dream of sending their children to the Ivy League. He and his wife, Joyce, a psychiatrist, know that Isabel will never join them. But raising Isabel has its own rewards. Isabel's sister, Olivia, 13, is "like a third parent," says Grinker. The family judges Isabel not by the standards of others but by how far she has come. "When Isabel achieves something, I feel like we're a team, like we all did it, and I feel incredibly rewarded," he says. For now, that is enough.

With KAREN SPRINGEN and MARY CARMICHAEL

cent of the population, the vast majority of whom are healthy—but a child who carries that variant also carries more than double the risk of the disease. Another, rarer gene, also implicated in brain development, was identified in August, and mutations on almost every chromosome have been suggested as possible culprits, including some implicated in rare disorders related to autism, such as Rett's Disorder and Fragile X. "There are perhaps hundreds of different causes, and I think the field is finally coming to grips with that," says UCLA neurogeneticist Dan Geschwind.

The NIMH is also newly interested in environmental factors that might set off the disorder in patients who are already genetically prone to it. U.S. scientists recently teamed up with counterparts in Denmark and Norway to screen samples of blood and amniotic fluid for possible toxins. And research is underway to see if viruses might be involved.

Scientists have also recently found several regions of the brain that differ from the norm in patients with autism (graphic), but none of them appears to be the sole problem. The key to the disorder likely lies not in one region but in the way the brain is wired. Some researchers pin the problem on defects in the brain's decentralized "mirror neuron" network, which allows healthy people to feel empathy. Other work shows that distant parts of the autistic brain are connected by too few fibers, while areas close to each other are connected by too many, tangled in thickets of "white matter."

The ultimate goal of all the research is to find not just a cause but a cure. Early behavioral therapy can produce stunning results, and parents have embraced it—the intensive clinic at UCLA has an 18-month waiting list. Still, says Insel, "it's hard to imagine that with a disease this disabling there's been nothing but behavioral treatments." Although few drug companies conducted promising trials this year, researchers are studying the antibiotic minocycline, the maternal hormone oxytocin, the drug Ecstasy, and a host of other candidates. The NIMH has also just begun a trial of chelation, a process that draws heavy metals out of the body. The therapy is popular among parents who maintain that mercury from vaccines prior to 1999 plays a role in autism—despite scientists' assurances that it doesn't. "The hypothesis is difficult to support," says Susan Swedo, the NIMH's chief of pediatrics and developmental neuropsychology. "But the anecdotal evidence is overwhelming. If this works, I want to know why." Thousands of scientists, parents and patients do too.