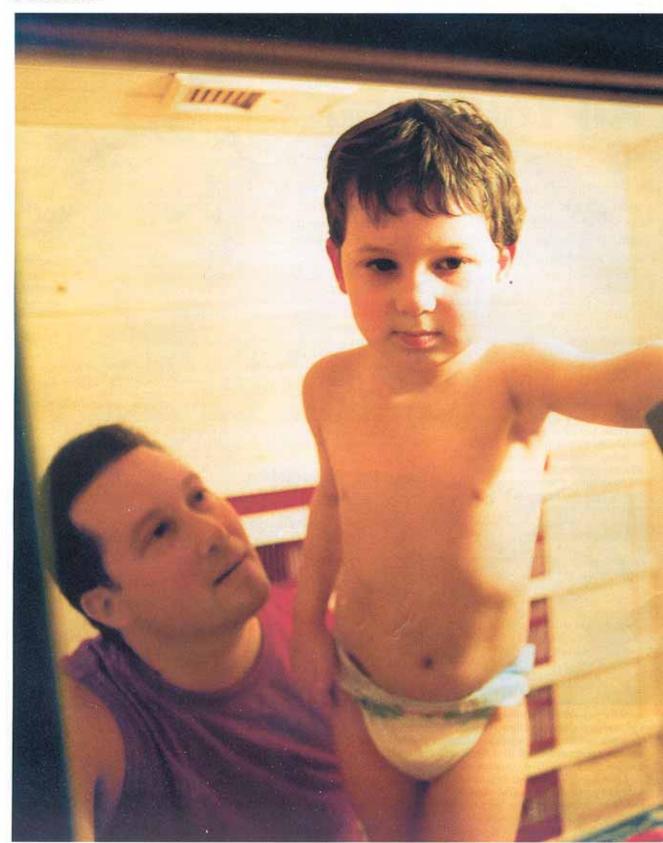


Health





Start?

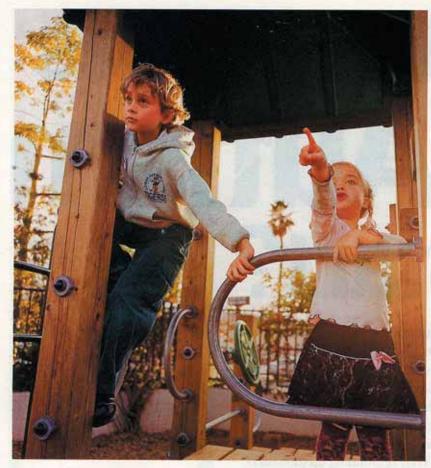
BY CLAUDIA KALB

T'S A WINTER NIGHT IN NORTHbrook, Ill., and brothers David and Jason Craven are on the move. They're watching a "Baby Beethoven" video. They're bouncing on a mattress in their basement playroom. They're climbing up their dad's legs. David, 7, and Jason, 5, with their mops of brown hair, look physically healthy. But both boys are suffering from a devastating developmental disorder: autism. David speaks only about 10 words, still wears diapers at night and Scientists are now looking for the earliest signs of the mysterious disorder as desperate parents hunt for treatments that may improve their children's lives.

sucks on a pacifier. Jason drinks from a baby bottle. Neither one can vocalize his glee as he plays. Neither one can communicate pain or joy in words. Neither one can say "I love you."

Since their sons were diagnosed, both at the age of 2, Barry and Dana Craven have tried a dizzying array of therapies: neurofeedback, music therapy, swimming with dolphins, social-skills therapy, gluten-free diets, vitamins, anti-anxiety pills and steroids. To reduce the boys' exposure to environmental chemicals, which the Cravens believe might aggravate their conditions, the couple replaced their carpeting with toxin-free wood floors

HOME THERAPY: BARRY CRAVEN AND HIS 5-YEAR-OLD SON JASON, IN THE SAUNA THEY USE TO TRY TO TREAT THE BOY'S AUTISM. JASON'S BROTHER, DAVID, 7, IS ALSO AUTISTIC. and bought a special water-purifying system. They even installed a \$3,500 in-home sauna, which they think will help remove metals like mercury and arsenic from the boys' bodies.



FAMILY TIME: WILLIAM MARQUIS, 11 (AND AUTISTIC), HANGS OUT WITH HIS SISTER HANNAH, 6, AT A SUPPORT-GROUP EVENT IN LOS ANGELES

Warm and loving parents, the Cravens spent \$75,000 on treatments last year alone. "I'm willing to try just about anything if it makes sense," says Dana.

In the six decades since autism was identified, modern medicine has exploded: antibiotics cure infections, statins ward off heart disease, artificial joints combat osteoarthritis. And yet autism, a vexing brain disorder, remains largely a mystery. Researchers still don't know what causes it, nor do they know how best to treat a condition that prompts one child to stop speaking and another to memorize movie scripts. With a tenfold spike in numbers over the past 20 vears-one in every 166 children is now diagnosed with an Autism Spectrum Disorder (ASD)-researchers, advocacy groups and the government are racing to improve the lives of children and their families, many of them emotionally and financially drained. This year the National Institutes of Health will spend \$99 million on autism research, up from \$22 million in 1997.

> Join Claudia Kalb for a Live Talk on autism, Wed., Feb. 23, at noon, ET, at Newsweek, com on MSNBC

Some of the most exciting new work involves efforts to spot clues of the disorder in infants as young as 6 months. In the complicated world of autism, where controversies reign and frustration festers, a two-word rallying cry is growing louder by the day: early diagnosis. This week the Centers for Disease Control and Prevention launches a \$2.5 million autism-awareness campaign, "Learn the Signs. Act Early." The goal: to educate health-care providers and parents about red flags, to intervene as quickly as possible—and to give kids with autism a shot at produc-

I haven't been this excited about research in a very long time.

-WENDY STONE, Vanderbilt University

tive, satisfying and emotionally connectives. "This is an urgent public-health coern," says the CDC's Catherine Rice.

ODAY, MOST CHILDR aren't even seen by speciali until they've passed their 2 birthdays, and many aren't dis nosed until at least the a of 3. Kids with Asperger's, on t higher-functioning end of ASD, may be ove looked until well into elementary school." we had a way of screening for autisi at birth and then could begin very early to retrain the brain, that would really be the ticket," says Dr. Thomas Insel, head of the National Institute of Mental Health, Scientists are now attempting to do just that. In a joint effort by the National Alliance for Autism Research and the National Institute of Child Health and Human Development. researchers at 14 sites, from Harvard to the University of Washington, are studying the baby siblings of children with autism, who have a genetic liability for the disorder. By measuring the infants' visual and verbal skills and their social interactions, scientists hope to identify early markers of autism before children turn 1. "I haven't been this excited about research in a very long time," says consortium member Wendy Stone of Vanderbilt University. "Not only are we getting clues about the earliest features of autism, but we're helping these families along the way."

Canadian researchers Dr. Lonnie Zwaigenbaum and Susan Bryson have enrolled 200 siblings, half of whom have been observed to the age of 2. Roughly 10 percent have been diagnosed with autism. Zwaigenbaum, of McMaster University in Ontario, says that signs of the disorder, though at first subtle, are often there from the very beginning. Preliminary data show that 6-montholds who are later diagnosed with autism generally have good eye contact, but they're often quieter and more passive than their peers. And they may lag behind in motor developments, like sitting up or reaching for objects.

The signs often become more obvious as children reach their 1st birthdays. By then, some show patterns of extreme reactivity, either getting very upset when a new toy or activity is presented or barely noticing at all. Others already exhibit repetitive behaviors characteristic of autism—rocking back and forth or becoming fixated on an object, like a piece of string dangling in front of their eyes. And they're less responsive to playful interactions with others. When a typically developing child plays peekaboo, her face lights up, she looks at the person she's playing with, she makes sounds, she reaches for the peekaboo blanket. Children with

am, by contrast, show little facial expres-They may not look at their playmate, it can take enormous energy to elicit a tion. "What's been striking," says Zwaibaum, "is the lack of response or the disstratt these activities can elicit."

The Baby Sibs consortium is also looking early physical markers of the disorder, rting with the size of children's heads. A dmark study published in 2003 found that Is with autism experienced unusually rapid head growth between 6 and 14 months. Consortium members want to see if their young siblings do, too. Scientists aren't sure what accounts for the increase, but one theory is that it has to do with an overgrowth of neuronal connections. Normally, the brain clears out biological debris as it forms new circuits. "Little twigs fall off to leave the really strong branches," says University of Michigan researcher Catherine Lord. In kids with autism, however, that pruning process may go awry.

In their hunt for neurological clues, scientists are unveiling the inner workings of the autistic mind. Using eye-tracking technology, Ami Klin, of the Yale Child Study Center, is uncovering fascinating differences in the early socialization skills of children with autism. Klin has found that when affected toddlers view videos of caregivers or babies in a nursery, they focus more on people's mouths—or on objects behind them—than Continued on page 50

Willing the World to Listen

A prominent family's journey: From despair to activism

BY SUZANNE WRIGHT

n March 1, 2004, my family and I huddled in a room at Columbia University Medical Center, awaiting the diagnosis of my then 2-year-old grandson. A physician entered and delivered the words we most feared: "He has autism."

Thus, our family's journey began-a long journey, still in its early stages, yet already more exhausting and frustrating than we could have imagined possible. We watched helplessly as a delightful, apparently normal toddler lost his ability to interact with the outside world. It was as if he'd been kidnapped or somehow had his mind and spirit locked in a dark hole deep within him. For a grandmother, this has been indescribably painful to witness. For his mother and father, it is heartbreaking.

Like anyone, I responded to the diagnosis with a frantic scramble for information.
What I found was profoundly discouraging. We had so many questions: Which therapies should our grandson have? How many hours? For how long? Who can provide the best guidance? Unfortunately, we found out what thousands of families already know: there are no good answers.

The Wright family—just like every family in this situation—was left to assemble a team of specialists on its own. If you have a loved one with autism, you'll try any-thing that might help. The difference between us and the average family is that we didn't have to sell our house or take on a huge burden of debt to pay for treatment. And the costs can be staggering—well out of the reach of most people, even those with generous health-insurance coverage.

I was surprised to learn that autism is the most widely

If you have a loved one with autism, you'll try anything that might help.

-SUZANNE WRIGHT, Autism Speaks

diagnosed developmental disability in the nation, affecting one in 166 children. You'd never suspect this from the resources devoted to the disorder. According to some estimates, autism research receives only \$15 million per year from private sources, compared with more than \$500 million for childhood cancers, muscular dystrophy, juvenile diabetes and cystic fibrosis—which, combined, are less common than autism.

To help close this gap in awareness and resources, my husband and friends have worked over the past few months to establish a new initiative dedicated to the more than 1.7 million people with autism in this country and their families, and to the additional 24,000 children who will be diagnosed this year. The project is called Autism Speaks, and we are up and running thanks to the overwhelming response from the



autism community and friends like Phil Geier, former chairman of Interpublic, and especially Bernie Marcus, the cofounder of the Home Depot. Autism speaks ... and it's time for the world to listen.

One of the main goals of Autism Speaks is to develop a central database of 10,000 - plus children with autism that will provide, for the first time, the standardized medical records that researchers need to conduct accurate clinical trials. This will significantly reduce the costs of the major studies that will lead to concrete progress. At the same time, we will push for muchneeded increases in publicsector and federal funding.

Every day, 66 children are diagnosed with autism. That's nearly three per hour. Why, given the alarming incidence rate, has there been no comprehensive national effort focused on autism? Here's one answer: such an effort must be driven by those with most at stake, the parents of autistic children. Yet these people—and I've met many in recent months—are exhausted. They are broke. And they are discouraged, It's all

they can do to get through the day, much less lobby Congress about funding.

Too many parents go to bed each night praying that one day their child will look them in the eye, smile and say "Mommy." My daughter is one of them. My husband and I are launching Autism Speaks for her and for all the families stricken by this disorder. The journey that began a year ago is now a march. Many good people—perhaps you

included—stand ready to join us. The pace is quickening, and God willing, we won't stop until we have conquered autism—one child, one voice at a time.

WRIGHT is the cofounder, with her husband, Bob, of Autism Speaks. Bob Wright is vice chairman of GE and chairman and CEO of NBC Universal. Learn more about Autism Speaks at autismspeaks.org or by calling 888-AUTISM-5.

What to Watch For

Autism is on the rise, but early diagnosis can lead to early intervention, and give kids a chance at better lives. Here are some early signs, plus a look at treatments and trends.

-JOSH ULICE

A TYPICAL BABY

Children develop at their own pace, so it's hard to know when an individual will learn a given skill. Here are some general guidelines to help mark your baby's progress.

at 7 months



Many children are able to:

- turn head when name is called
- smile back at another person
- respond to sound with sounds
- menjoy social play (such as peekaboo)

How Common Is It?

The number of children diagnosed with autism has jumped 10 times in the last 20 years, and more children are now treated at a younger age. These increases may be due in part to more aggressive screening.

Nationwide:

1 child in

166 has autism

Boys outnumber girls



Autism Spectrum

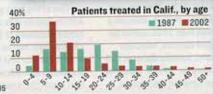
- Autism: Severe language problems, lack of interest in others, repetitive behaviors, resistance to change, irrational routines.
- Asperger's: Relatively strong verbal skills, but trouble reading social situations and sharing enjoyment, obsessive interests.
- PDD-NOS: Known as 'atypical autism,' kids have less severe social impairments.
- Childhood Disintegrative
- Disorder (CDD): Normal growth for 2 to 4 years, then autismlike symptoms develop.
- Rett Syndrome: Similar pattern as CDD but occurs earlier and mostly in girls.

at 1 year



Many children are able to:

- use simple gestures (wave 'bye-bye')
- make sounds such as 'ma' and 'da'
- imitate actions in play (clap when you clap)
- respond when told 'no'

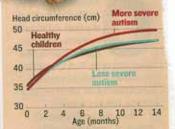


In the Brain

Studies show that children with autism undergo abnormal brain development from early infancy. Researchers found that affected kids start out with slightly smaller heads than average, then undergo explosive brain growth, with severe cases growing the fastest.



Brain of a typical 3-year-old



at 18 months



Many children are able to:

- do simple pretend play (e.g., 'talk' on a toy pho-
- point to interesting objects
- look at objects that you point out
- use several individual words unprompted



INTERVENTION: ALEX BROGAN AND HIS MOTHER, LISA, WORK WITH THERAPIST JOY SEREDNESKY IN OHIO. ALEX'S TREATMENT, CALLED FLOORTIME, USES PLAY TO TEACH COMMUNICATION SKILLS. \$12,500 cost for average special-

\$18,800

cost for a student with autism per year

atments

RAPY: A child may receive more ne type at a time, along with and occupational therapy.

lied Behavioral Analysis: ive one-on-one drills instill social/ ige skills through positive reinforcement.

ortime: This child-directed approach

.ACCH: Uses children's individual ests to motivate them to learn in a stured environment.

ocial Stories: Uses stories to teach social and give insight into others' perspectives.

ECS: Helps build communication skills ugh the use of pictures.

DI: Encourages experience sharing and hasizes parental involvement.

2 years

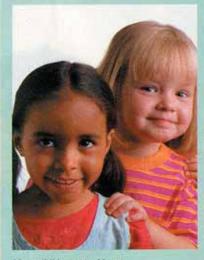


any children are able to: say two- to four-word phrases follow simple instructions

emonstrate interest in other children vint to an object or picture when named DRUGS: Nothing treats the core symptoms of autism, but drugs can ease behaviorial problems.

- Risperidone: This anti-pyschotic was shown to decrease aggression and hyperactivity.
- SSRIs: Antidepressants like Prozac may reduce repetitive behaviors.
- Anticonvulsants: Drugs like Depakote are being tested for treating aggression.
- Stimulants: Ritalin (left) may lessen hyperactivity.

at 3 years



Many children are able to:

- show affection for playmates
- use four- to five-word sentences
- imitate adults and playmates
- play make-believe with dolls, animals, people

Distribution

There are about 130,000 kids with autism ages 6 to 17 in public schools around the country. Their numbers have risen consistently across all states.

at 4 years



Many children are able to:

- use five- to six-word sentences
- follow three-step commands ('get dressed,
- comb your hair and wash your face')
- cooperate with other children

More Information

- Autism Coalition: autismcoalition.org
- Autism Soc. of America: autism-society.org
- CDC: cdc.gov/ncbddd/autism/actearly
- Cure Autism Now: cureautismnow.org
- First Signs: firstsigns.org
- Nat. Alliance for Autism Research: naar.org
- NIMH: nimh.nih.gov/publicat/autism.cfm

Autism rates per 1,000 children ages 6-17



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Continued from page 47

on their eyes. Klin's toddler study echoes findings in adults and adolescents with autism when they watched clips of "Who's Afraid of Virginia Woolf?" "Richard Burton and Elizabeth Taylor were engaged in a passionate kiss, and they're focusing on the light switch," says Klin. "Our goal is to identify these vulnerabilities as early as possible."

IGHT IT BE THAT THE autistic brain's operating platform is different, as if it's a Mac in a world of PCs? Functional MRI scans show that the brain's "fusiform face area," the control tower for face recognition, is underactive in people with autism. The more severe the disorder, the more disabled the fusiform. But is it actually dysfunctional? Or is it just not interested in people? In an intriguing early study, Yale's Robert Schultz took brain scans of a child with autism who had trouble distinguishing human faces but loved the cartoon character Digimon. "Lo and behold," says Schultz, "his fusiform showed strong activity." Schultz and James Tanaka at the University of Victoria in Canada are hoping computer games can help kids with autism learn how to engage with human faces and identify emotions. The children follow directions to shoot at smiley faces or click on the guy who looks sad. In "Emotion Maker," they choose features-angry eyes, a scowling mouth-to create their own faces. And in "Who's Looking at Me?" they scan an array of faces to sensitize them to eve contact. So far, says Schultz, the kids appear to be improving. But will it help change the course of their lives? "That's the milliondollar question," he says.

An intellectual thief, autism infiltrates children's brains, stalling or stealing cognitive and social development. In classic autism, babies fail to coo or babble by their 1st birthdays. Or words that do develop ("dada," "up," "toy") inexplicably disappear. One-year-olds don't

Autism on NBC

If you want to learn more, tune in to these programs from Feb. 21 to 25.



Today": Five days of coverage at 7 a.m., ET-adults with autism, sibling stress, legal hurdles and more



"NBC Nightly News": Three reports from Robert Bazell, including leadingedge research, at 6:30 p.m., ET



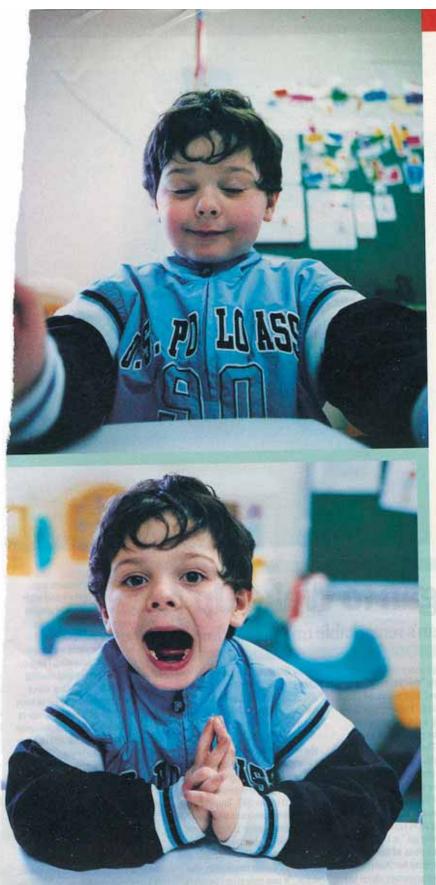
MSNBC: Live interviews with autism experts and parents of autistic children, daily at 10:30 a.m., ET



CNBC's "Power Lunch" (12: 30 p.m., ET) and "Closing Bell" (4:45 p.m., ET): The costs of autism







ROLE-PLAYING: BLAISE KRUK, 5, ATTENDS THE AERO EDUCATIONAL CENTER, A PUBLIC SCHOOL IN BURBANK, ILL., WHERE CHILDREN WITH AUTISM LEARN TO COMMUNICATE

respond to their names. A child once bursting with potential finds spinning tops more captivating than her mother's smile. Kids with Asperger's may not be as closed off, but they suffer severe social deficits. Many are verbal fanatics, immersing themselves in longwinded monologues about obscure topics, like fat fryers or snakes. Klin recalls a child who bowed and spoke in Shakespearean English, "almost as if I had plucked him from 14th-century Verona." Such oddities can make these children social pariahs. Baffled by human interactions and frustrated by their inability to make friends, some kids spiral into debilitating fits of anxiety and depression. Many children on the autism spectrum will never live independent lives. "We're talking about children who need lifelong care," says NIMH's Insel. "This is an astonishingly devastating disease."

And its current treatment is all over the map. Every day, it seems, there's a new "cure." With no known cause and no clear guidance, parents must navigate a maze of costly therapies, most of which have little hard-core science to prove their effectiveness. Many

I am willing to try just about anything if it makes sense.

-DANA CRAVEN, mother of two boys with autism

children now take medications, ranging from anticonvulsants (about one third suffer from seizures) to stimulants like Ritalin to calm hyperactivity. Low doses of antidepressants such as Prozac may help reduce the severity of repetitive behaviors. And risperidone, an anti-psychotic drug, can quell aggression and tantrums, says Dr. Christopher Mc-Dougle, of the Indiana University School of Medicine. The drug, whose side effects include weight gain and sedation, is now before the FDA and could become the first medication approved specifically for autism.

Drugs, however, won't help a child learn to speak. One of the few treatments that just about everyone agrees is critical is behavioral intervention, which uses word repetition, game-playing and specialized exercises to develop a child's language and social skills. At the Lovaas Institute in Los Angeles, senior instructor Sona Gulyan engages Adam Ellis, who turns 4 next month, in language drills

Health

known as discrete trials, "Say 'hi," says Gulyan, Adam, a chubby-cheeked little boy in jeans and a white T shirt, responds with a "k" sound. "No, 'hi," says Gulyan. After several failed attempts, Gulyan switches the focus. "Do this," she says, pointing to her nose. Adam imitates the gesture and is congratulated. And then it's back to the original task: "Say 'hi'." Finally, success-and an orange balloon as a reward. In 1987, founder Ivar Lovaas reported that children who received an average of 40 hours a week of his intensive one-on-one therapy called Applied Behavior Analysis increased their IQs by 30 points, compared with a control group. Other studies, however, have been mixed, and critics believe the program is too militaristic. But for Adam's mother, Megan, it's progress that matters. "He has mastered so many skills," she says. "It's just amazing."

Things are more relaxed at Cleveland's Achievement Centers for Children, where Lisa and Tim Brogan play with their son, Alex. Alex is learning to communicate through an intervention called Floortime, which focuses on a child's individual strengths and his relationships with others. Kids learn to engage with their parents through "circles of communication." If Alex wants to line up toy cars in a row, his dad will join him, then nudge one out of place. The move prompts Alex to interact with his father-a circle of communication-rather than isolate himself with the toys. "We have come such a very long way," says Lisa.

Children with autism have as many styles and personalities as any group of toddlers. A



'My Mind Began to Wake Up'

Lost and found: One woman's remarkable transformation

BY MELINDA HENNEBERGER

ue Rubin doesn't remember much about the first 13 years of her life: "Sadly, I was locked in autism." And from inside that locked-up place, "I actually only remember waving to regular school" and at regular life. "That's a nice way to put it, Suze," her mother, Rita Rubin. says ruefully. Sue used to beat her head against the concrete floor at her school, and regularly bit, kicked and pinched her parents. She was considered severely mentally retarded, with an IQ of 24,

and through years of what her mother calls "every therapy you can imagine," she remained utterly unresponsive. "Holding Sue was like holding a sack of potatoes. because you got nothing back," Rita says. That slowly began to change in the fall of 1991, after a school psychologist in Whittier, Calif., where the Rubins live, suggested that Sue try communicating with a keyboard.

"As I began to type, my mind began to wake up," is how Sue, now 26, describes all that followed in the screenplay for "Autism Is a World," a documentary about her

life by Gerardine Wurzburg. In the Oscar-nominated film. Sue writes about how words themselves became her way-not out of autism, but into the wider world.

A year after Sue began to type, she enrolled in mostly honors and advanced-placement high-school classes, eventually graduating with a 3.98 grade-point average, scoring 1370 on the SAT. Today she's a junior history major at Whittier College and lives semi-independently, with an aide, in her home a few blocks from campus. In a paper she presented earlier this month, she wrote, "It was only after I began to

type that my brain became organized enough to understand what was going on in the world around me ... I became aware of people and their killer personal lives. I also realized the world was larger than Whittier, California ... I began listening to the news and reading the newspaper ... Thinking about world events wouldn't seem to have anything to do with learning how to control autistic behaviors. However, that is what happened. As I became more aware of the world around me I also became more aware of myself and my autism."

As always, however, selfawareness was a mixed blessing: "It was awful seeing how different I am," she types in an interview. It bothers her, for example, that she still feels compelled to carry around a handful of plastic spoons. "I knowingly contribute to my look-

ING: JASON KLEIN, A CONTROL SUBJECT, S PART IN A YALE EYE-TRACKING STUDY ING FOR EARLY SIGNS OF AUTISM. AFFECTED FOCUS MORE ON MOUTHS THAN EYES.

wioral intervention that suits one child is parent) won't necessarily work for anr. Many treatment centers now mix techies from different approaches, including of the newest on the block: Relationship relopment Intervention, or RDI. Here, ents learn how to use everyday events as chable moments. A trip to the grocery ore, for example, becomes an opportunity kids to learn to adapt to sensory overid-the chatter of shoppers, 100 different nds of cereal. In the past, Pam Carroll's son, organ, now 9, was fixated on instant oateal with blueberries, and he melted down if wasn't available. Now he roams the aisles Gainesville, Fla., and helps his mom 10p. Linda Andron-Ostrow, a clinical social orker in Los Angeles, likes the way RDI mpowers parents and allows for creative ninking. "Life isn't structured," she says.

With autism's medley of symptomsvhich can include a heightened sensitivity to sound and picky eating habits-many famiies search for alternative treatments. Kacy

Dolce and her husband, Christopher, recently took their son, Hank, 4, to see Mary Ann Block, an osteopath in Hurst, Texas, for a \$2,500 assessment. Block prescribes vitamins and minerals, diets free of wheat and dairy, and a controversial treatment, chela-

tion, which strips the body of metals like mercury. Block believes these toxins could come from vaccines and are at the core of autism. Mainstream doctors, pointing to scientific studies showing no connection, worry that chelation puts children at serious risk. Despite the possibility of dangerous side effects, like liver and kidney problems, the Dolces say they'd consider it. "We don't know enough yet to say no," says Kacy. "I'll do anything to help our child."

HAT PARENTS REALLY need is a road map. Earlier this month six U.S. medical centers joined forces to launch the Autism Treatment Network, which will evaluate therapies, pool data and, ultimately, create guidelines. "We can't have parents chasing down the latest treatment," says Peter Bell of Cure Autism Now, a research and advocacy group allied with the effort. "We need to understand what works." At the forefront of ATN is Massachusetts General's Ladders program, where Dr. Margaret Bauman is using a multidisciplinary approach. In addition to offering standard regimens like

physical therapy and behavioral intervention. Bauman assesses overall health. When she saw a teenager crying and twisting her body, symptoms other doctors attributed to autism, Bauman sent her to a gastroenterologist, who found ulcers in her esophagus. The writhing was caused by pain. A boy's head-banging went away after he was treated for colitis. "We really have to start thinking out of the box," says Bauman.

And thinking early. Today many kids aren't getting treatment until well after their 3rd birthdays. Diagnosing an infant with autism at 6 months or a year-maybe even one day in the delivery room-could mean the difference between baby steps and giant leaps. At the Kennedy Krieger Institute in Baltimore, a handful of 2-year-olds toddle at the next frontier in autism treatment. The children are part of an NIH-funded study run by Rebecca Landa to see if early intervention, before the age of 3, can improve the trajectory of cognitive and social development. As Landa looks on, David Townsend fusses and stamps his feet. Then, he notices his twin sister, Isabel, turning the pages of "Ten Little Ladybugs." David looks at Isabel. watches her hands, then flips a page himself, accomplishing what autism experts call

"joint engagement." "That was beautiful," says Landa. A fleeting moment, a developmental milestone-and, if all goes well, a new world of possibilities for a sweet little boy with dimples.

> With KAREN SPRINGEN, ELLISE PIERCE, JOAN RAYMOND and JENNY HONTZ

listening to the news and reading the newspaper."

-SUE RUBIN, Film writer with autism

ing retarded," by doing so, she says in the film. "But spoons are my comfort. I cannot explain how or why I need them, I just do."

Sue still can't communicate verbally beyond a few phrases: instead, she types into a machine that then speaks each sentence for her at the push of a button. Critics of facilitated communication, the keyboard method Sue uses, believe it usually reflects not the thoughts of people who have autism, but of their aides, who may be unintentionally guiding them. Sue, however, has typed on her own for several years now, and had a lot to say-on autism, politics and her favorite pastime, playing the ponies-in a recent interview at her home, where she was waiting at the door, holding her bouquet of spoons.

When she first started typing,

Sue used an impressive array of swear words that shocked her parents, and she still loves to jolt new acquaintances out of any preconceived notions they might have about her interior life. What she really enjoys, she says, is a day at the track, or better, a trip to Vegas, where she stands on a stool to play craps. She also likes Tom Petty, Bush bashing, shoe shopping-the day we met, she

BUSY: COLLEGE STUDENT RUBIN LOVES TO PLAY THE PONIES

was wearing pink Uggs-and the occasional touch of sarcasm: "I'm actually just being a jerk," she tells me at one point. "I enjoy giving answers that Melinda does not expect."

Sue is most determined to dispel some common ideas about autism. She insists, for example, that people with autism are capable of empathy. She understands how others feel, she says, even if their problems sometimes strike her as trivial in comparison to her own daily struggles. And it bothers her that her face does not easily register all she does feel. Yet she manages to convey great urgency when she types: "Tell everyone that nonverbal autistic people are intelligent!"

