



With Chadwick helping to stabilize her right wrist and her mother watching, a girl thought to be incapable of learning to read or write slowly typed, "I love Mom."

A year and a half later, Hannah sits with her tutor at a small computer desk in her suburban home outside New York City. Facilitated communication is controversial (critics complain that it's often the facilitator who is really communicating), but it has clearly turned Hannah's life around. Since her breakthrough, she no longer spends much of her day watching Sesame Street and Blue's Clues. Instead, she is working her way through high school biology, algebra and ancient history. "It became obvious fairly quickly that she already knew a lot besides how to read," says her tutor, Tonette Jacob.

During the silent years, it seems, Hannah was soaking up vast storehouses of information. The girl without language had an extensive vocabulary, a sense of humor and some unusual gifts. One day, when Jacob presented her with a page of 30 or so math problems, Hannah took one look, then typed all 30 answers. Stunned, Jacob asked, "Do you have a photographic memory?" Hannah typed "Yes."

Like many people with autism, Hannah is so acutely sensitive to sound that she'll catch every word of a conversation occurring elsewhere in the house, which may account for much of her knowledge. She is also hypersensitive to visual input. Gazing directly at things is difficult, so she often relies on her almost preternatural peripheral vision. Hannah's newfound ability to communicate has enabled her intellect to flower, but it also has a dark side: she has become painfully aware of her own autism. Of this, she writes, "Reality hurts."

MORE THAN 60 YEARS AFTER AUTISM WAS first described by American psychiatrist Leo Kanner, there are still more questions than answers about this complex disorder. Its causes are still uncertain, as are the reasons for the rapidly rising incidence of autism in the U.S., Japan, England, Denmark and France. But slowly, steadily, many myths about autism are falling away, as scientists get a better picture of what's going on in the bodies and brains of people with autism and as more of those who are profoundly affected, like Hannah, are able to give voice to their experience. Among the surprises:

Autism is almost certainly, like cancer, many diseases with many distinct causes. It's well known that there's a wide range in the severity of symptoms-from profound disability to milder forms like Asperger syndrome, in which intellectual ability is generally high but social awareness is low. Indeed, doctors now prefer the term Autistic Spectrum Disorders (ASD). But scientists suspect there are also distinct subtypes, including an early-onset type and a regressive type that can strike as late as age 2.

Once thought to be mainly a disease of the cerebellum-a region in the back of the brain that integrates sensory and motor activity, autism is increasingly seen as a pervasive problem with the way the brain is wired. The distribution of white matter, the nerve fibers that link diverse parts of the brain, is abnormal, but it's not clear how much is the cause and how much the result of autism.

■The immune system may play a critical role in the development of at least some types of autism. This suggests some new avenues of prevention and treatment.

Many classic symptoms of autismspinning, head banging, endlessly repeating phrases-appear to be coping mechanisms rather than hard-wired behaviors. Other classic symptoms-a lack of emotion, an inability to love-can now be largely dismissed as artifacts of impaired communication. The same may be true of the supposedly high incidence of mental retardation.

The world of autism therapy continues to be bombarded by cure-of-the-day fads. But therapists are beginning to sort out the best ways to intervene. And while autism is generally a lifelong struggle, there are some reported cases in which kids who were identified as autistic and treated at an early age no longer exhibit symptoms.

THE CURIOUS INCIDENCE

DR. THOMAS INSEL, DIRECTOR OF THE National Institute of Mental Health (NIMH), which funds much of the nation's autism research, remembers a time when the disorder was rarely diagnosed. "When my brother trained at Children's Hospital at Harvard in the 1970s, they admitted

the hospital brought all of the residents through to see," says Insel. "He said, 'You've got to see this case; you'll never see it again."

Alas, he was mistaken. According to the Centers for Disease Control and Prevention (CDC), about 1 in 166 American children born today will fall somewhere on the autistic spectrum. That's double the rate of 10 years ago and 10 times the estimated incidence a generation ago. While some have doubted the new figures, two a child with autism, and the head of surveys released last week by the CDC were

in keeping with this shocking incidence.

No one can say why the numbers have soared. Greater awareness and public health campaigns to encourage earlier diagnosis have surely played a part, since in the past, many such children were probably labeled retarded or insane and hidden in institutions. But environmental factors may also be contributing to the spike. To get to the bottom of that mystery and others, federal funding for autism research has more than tripled in the past decade, to \$100 million, although it pales in comparison with the estimated \$500 million spent on childhood

mental Health and Disease Prevention at the University of California at Davis, toxiwith autism. He's testing for 17 metals, traces of pesticides, opioids and other toxicants. In March Pessah caused a stir by releasing a study that showed that even the low level of mercury used in vaccines preserved with thimerosal, long a suspect in autism, can trigger irregularities in the immune-system cells-at least in the test tube. But he does not regard thimerosal (which has been removed from routine childhood vaccines) as anything like a smoking gun. "There's probably no one trigger that's causing autism from the environmental side," says Pessah, "and there's no one gene that's causing it."

urine and tissue samples from 700 families

Indeed, most researchers believe autism arises from a combination of genetic vulnerabilities and environmental triggers. An identical twin of a child with autism has a 60% to 90% chance of also being affected. And there's little doubt that a vulnerability to ASD runs in some families: the sibling of a child with autism has about a 10% chance of having ASD. Gene scientists working on autism have found suspicious spots on chromosomes 2, 5, 7, 11 and 17, but there are probably dozens of genes at work. "We think there are a number of different autisms, each of which could have a different cause and different genes involved," says David Amaral, research director of the MIND (Medical Investigation of Neurodevelopmental Disorders) Institute, also at U.C. Davis.

area plays a role in sizing up threats

in the environment and in emotion

and social behavior. Its size may be

related to the high level of anxiety in

autistic people. Research shows their

amygdala is activated when looking at

The <mark>hippocompute</mark> is about 10% larger than normal. This area is vital

to memory. One possibility is that

this structure becomes enlarged

because autistic children rely on

most people process elsewhere.

lobes, is overloaded with white

memory to interpret situations that

matter. This region plays a key role

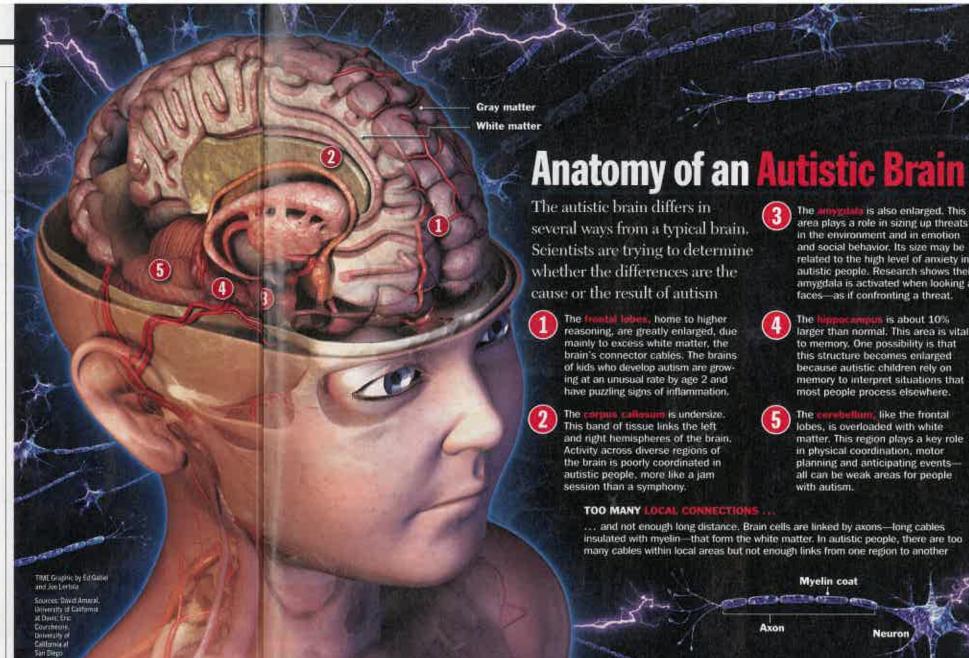
planning and anticipating events-

all can be weak areas for people

like the frontal

faces—as if confronting a threat.

Amaral is heading MIND's efforts to assemble a database of clinical, behavioral and genetic information on 1,800 autistic kids. One goal is to clearly define autism subtypes. "It's hard to do the genetics if you're talking



cancers, which affect fewer youngsters. At the Center for Children's Environcologist Isaac Pessah is studying hair, blood,

Roughly 1 in 166 American children born today will fall somewhere on the autistic spectrum. That's more than three times the number with juvenile diabetes

BEHAVIOR

about four or five different syndromes," says NIMH chief Insel. "Does the presence of seizures define a separate illness? What about the kids who seem to develop normally for the first year and a half and then regress—is that a separate thing?" And what about the large number of autistic kids who have serious gastrointestinal problems and the many with immune dysfunctions—are they distinct subtypes?

Amaral and colleague Judy Van de Water believe they are onto a major discovery about the origins of at least one type of autism-a strongly familial variety. They have detected aberrant antibodies in the blood of kids from families with a pattern of ASD and, significantly, in mothers with more than one autistic child. "These antibodies are actually raised against proteins in the fetal brain," says Amaral, who recently submitted a paper on the discovery. The working hypothesis is that these antibodies may alter brain development in ways that lead to autism. If correct, the finding could lead to a maternal blood test and the use of a therapy called plasmapheresis to clear antibodies from the mother's blood. "You get a sense of the excitement," says Amaral, "if you could prevent, say, 20% of kids from getting autism. But we don't want to raise false hopes."

THE AUTISTIC BRAIN

WHETHER THE CAUSE IS MATERNAL ANTIbodies, heavy metals or something else, there is no question that the brains of young children with autism have unusual features. To begin with, they tend to be too big. In studies based on magnetic resonance imaging (MRI) and basic tape-measure readings, neuroscientist Eric Courchesne at Children's Hospi-

tal of San Diego showed that while children with autism are born with ordinary-size brains, they experience a rapid expansion by age 2—particularly in the frontal lobes. By age 4, says Courchesne, autistic children tend to have brains the size of a normal 13-year-old. This aberrant growth is even more pronounced in girls, he says, although for reasons that remain mysterious, only 1 out of 5 children with autism is female. More recent studies by Amaral and others have found that the amygdala, an area associated with social behavior, is also oversize, a finding Amaral believes

Eye Contact

Antistic lides often look at the mouth rather than the eyes of someone speaking. A good teacher—and Silly String—can change that





is related to the high levels of anxiety seen in as many as 80% of people with autism.

Harvard pediatric neurologist Dr. Martha Herbert reported last year that the excess white matter in autistic brains has a specific distribution: local areas tend to be overconnected, while links between more distant regions of the brain are weak. The brain's right and left hemispheres are also poorly connected. It's as if there are too many competing local services but no long distance.

This observation jibes neatly with imaging studies that look at live brain activity in autistic people. Studies using functional MRI show a lack of coordination among brain regions, says Marcel Just, director of Carnegie Mellon's Center for Cognitive Brain Imaging in Pittsburgh, Pa. Just has scanned dozens of 15- to 35-year-old autistic people with IQs in the normal range, giving them thinking tasks as he monitors their brain activity. "One thing you see," says Just, "is that [activity in] different areas is not going up and down at the same time. There's a lack of synchronization, sort of like a difference between a jam session and a string quartet. In autism, each area does its own thing."

What remains unclear is whether the interconnectivity problem is the result of autism or its cause. Perhaps all that excess wiring is like the extra blood vessels around the heart of a person who has suffered a heart attack—the body's attempt to route around a problem. Or perhaps the abnormal growth of the brain has to do with the immune system; researchers at Johns Hopkins have found signs that autistic brains have chronic inflammation. "It's impossible to tell the chicken from the egg at this point," Just says.

Autistic people have been shown to use their brains in unusual ways: they memorize alphabet characters in a part of the brain that ordinarily processes shapes. They tend to use the visual centers in the back of the brain for tasks usually handled by the prefrontal cortex. They often look at the mouth instead of the eyes of someone who is speaking. Their focus, says psychologist Ami Klin of Yale's Child Study Center, is "not on the social allegiances—for example, the longing gaze of a mother—but physical allegiances—a mouth that moves."

Do these differences reflect fun-

Planning

Transitions are hard for autistic kids. The visuals on this schedule help Eric anticipate the plan and indicate when he needs a break damental pathology, or are they downstream effects of some more basic problem? No one knows. But the fact that early intervention brings better results for children with ASD could be a clue that some of the odd brain anatomy and activity are secondary—and perhaps even preventable. Studies that look at whether early therapy might help normalize the brain are beginning at York University in Toronto, but results are probably years away.

AUTISM FROM THE INSIDE IN THE MEANTIME, 300,000 SCHOOL-AGE American children and many adults are at-



BRAIN SCAN This geodesic camera is being used in conjunction with Wills to help scientists peer into the brains of autistic children

tempting to get through daily life with autism. The world has tended to hear from those who are highest functioning, like Temple Grandin, the author and Colorado State University professor of livestock behavior known for designing humane slaughterhouses. But the voices of those more severely affected are beginning to be heard as well. Such was the case with Sue Rubin, 27, a college student from Whittier, Calif., who has no functional speech and matches most people's stereotyped image of a retarded person; yet she was able to write the narration for the Oscar-nominated documentary about her life, Autism Is a World.

What such individuals have to say about their experience is offering new clues to their condition. It also conforms remarkably to what scientists see inside their brains. By and large, people with ASD have difficulty bringing different cognitive functions together in an integrated way. There is a tendency to hyperfocus on detail and miss the big picture. Coordinating volition with movement and sensation can be difficult for some. Chandima Rajapatirana, an autistic writer from Potomac, Md., offers this account: "Helplessly I sit while Mom calls me | Dan Cray/Los Angeles

to come. I know what I must do, but often I can't get up until she says, 'Stand up,'" he writes. "Thel knack of knowing where my body is does not come easy for me. Interestingly I do not know if I am sitting or standing. I am not aware of my body unless it is touching something ... Your hand on mine lets me know where my hand is. Jarring my legs by walking tells me I am alive."

Such descriptions shed light on seemingly self-destructive behavior like biting, scratching, spinning and head banging. For people like Rajapatirana, banging against a wall can be a useful way to tell, quite literally, where their head is at. "Before we extinguish [such behaviors], we need to understand what they are telling us," writes Judith Bluestone, a Seattle-based therapist who is autistic, in The Fabric of Autism.

In his new book Send in the Idiots, British journalist Kamran Nazeer, who is also autistic, describes the need for repetitive motions or words as a search for "local coherence" in a world full of jarring randomness. He also conveys the social difficulties: "Striking up conversations with strangers," he writes, "is an autistic person's version of extreme sports." Indeed, at a recent retreat for people with ASD, attendees wore colored tags indicating their comfort level with spontaneous conversation: red meant don't approach, yellow meant talk if we've already met, green indicated, "I'd love to talk, but I'm not good at initiating."

Perhaps the worst fate for a person

kids, Merzenich wonders, "are living in a

well where no one can hear them"?

Luckily for Hannah, her voice and thoughts are being heard. Since learning to type, she has begun to speak a few words reliably-"yes," "no" and the key word "I"to express her desires. All this seems miraculous to her parents. "I was told to give up and get on with my life," says her mother. Now she and her husband are thinking about saving for college. -With reporting by

Early intervention in a well-run program is the key to helping autistic children reach their potential. A close-up look at two approaches

By CLAUDIA WALLIS

ROM THE MOMENT PARENTS ABSORB the shock that their child may be autistic, they enter a dizzying world of specialists, therapists and, alas, purveyors of snake oil. Getting the right help quickly is paramount, but it is hard to make good decisions when you are in a panic or fighting despair.

For the past 20 years, the dominant way

Skinner, who showed-mostly in animalsthat behavior can be altered with carefully repeated drills and rewards. In 1987, Ivar Lovaas at UCLA published a small study with huge repercussions. He reported that 9 out of 19 autistic children taught for 40 hours a week with behaviorist methods had big jumps in IQ and were able to pass first grade; only 1 out of 40 in control groups did so. It was the first bright ray of hope in autism.

Recent years have brought questions about the ABA model. When Lovaas protégé Tristram Smith tried to replicate the 1987 findings in a 2000 study, he got a more modest success rate on academic measures and virtually no gains in social behavior. Others, autistic student. Dur Cherry of Celebrate the Children gats down on the floor and enters like world

meanwhile, have devised new ways of working with autistic kids. One of the best known was developed by child psychiatrist Stanley Greenspan, who spent 15 years studying infant development at the National Institute of Mental Health. His method, called DIR (developmental, individual-difference, relationship based), has as its premise the idea that an exchange of emotional signals, initially between mother and infant, form the basis for learning in childhood, Greenspan trains parents and teachers to engage the emotions



While the majority of U.S. programs for autistic children are based on ABA tech-

niques, DIR has made inroads, and many programs now mix elements of both. How do the techniques differ in practice? To find out, TIME visited two schools, each a model for one school of thought.

ALPINE LEARNING GROUP

IT'S EASY TO SEE WHY A PARENT would fight to get a child placed here. Who wouldn't want this calm, orderly world for an anxious child with all the sensitivities of autism? Alpine, in Paramus, N.J., has 28 students, ages 3 to 21, in six gleaming, light-filled classrooms. The staffto-child ratio is 1 to 1. The \$72,223 tuition is covered by the state-federal law requires a free education for children with disabilities in an "appropriate" setting.

At Alpine, every goal, every lesson, every response is carefully documented in binders that track each child's progress. That is the rigorous heart of ABA, explains executive director Bridget Taylor, who cofounded the school in 1988. "I'm a scientist-practitioner; I need data," says Taylor, a certi-

fied ABA therapist with a Ph.D. in psychology. The binder for Jodi DiPiazza, 4, is easily seven inches thick, though Jodi has been at Alpine less than a year. Like most other children at the school, she started ABA therapy at home as a toddler.

In her classroom, Jodi sits quietly at a small table with a teacher. They take turns looking at photos and using a complete sentence to describe the scene ("The girl is riding a bike"). Each correct answer earns Jodi a sticker on a chart; with enough stickers she can choose a reward. ABA was once famous for its M&M rewards, but better programs now tailor positive reinforcement to the child's preferences-a favorite activity, a hug or, in the case of one Alpine student, a packet of ketchup. Though Jodi didn't talk at all | cepts that," says Taylor. "Fifty percent of the

until age 3, she speaks well and is mastering skills quickly with the help of two hours of tutoring in the evening. "From the moment she wakes up till she goes to sleep, everything is structured," says her mother Michelle, who is thrilled with Jodi's progress.

Taylor says 29% of her students, most from ages 5 to 8, get mainstreamed into regular schools, generally with an aide.

Two Systems

a sticker for herself by locating

the correct date on a calendar.

teachers reward students with

Many who remain at Alpine have limited

language skills; some of the older students

use electronic devices to express basic de-

sires. The ritualistic behavior that is char-

acteristic of autism is strongly suppressed.

"Hands down," says a teacher to a child who

begins to flap. "We're not a culture that ac-

and hig grins

rewdy shouts of encouragement

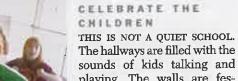
In group activities at CTC, bottom.

battle is addressing behavior to look good."

boys, the focus is on life skills. Johnathan learns to type a grocery list, which he and an instructor will later take shopping. Another boy, learning to use a camera, asks visitors whether he may take their picture. He uses the same words and intonation each time he asks. Robotic behavior, lack of

In a classroom with four teenage

emotion and inability to use trained skills outside school are some of the shortcomings critics attribute to ABA. A boy who has learned to play Nintendo games at Alpine, for instance, reverts to simply switching the game on and off when at home. Proponents concede certain weak points, but they also note a long record of results. Says Tristram Smith of the University of Rochester: "Anything outside ABA is basically experimental at this point."



The hallways are filled with the sounds of kids talking and playing. The walls are festooned with banners, photographs and artwork. Parents always ask whether it's too much stimulation, says director Monica Osgood, but the school wants its students to adapt to the "real world." Celebrate the Children (CTC), which costs \$47,856 a yearpaid by the state-is one of a growing number of DIR

schools. It opened its doors in Stanhope, N.J., in January 2004 with just three students. It now has 41, from toddlers to teens, and is still expanding fast.

CTC emphasizes the expression of emotion and spontaneous thinking. Rather than work on a highly specific skill, DIR activities tend to include complex social interactions that build many skills at once. In a classroom for 5-to-9-year-olds, eight kids sit in a circle playing a game in which they pick an activity card and a card showing a classmate's face. Children earn cheers as they perform the designated activity with that classmate (giving Olivia a high five, hugging Alex). Instead of tangible rewards, shouts of encouragement, a sense of accomplishment and what Greenspan calls the "warm, pleasurable

feelings" that come from human interaction serve as a reinforcement for learning. In a classroom of 11-to-14-year-olds, kids are asked to stand in a narrow row between two strips of blue crepe paper representing water. The challenge: to arrange themselves in height order without stepping over the lines and falling "off the boat." The task combines communication skills, problem solving and visual, spatial skills. Teachers at CTC are trained to work on sensory issues and use the principles of occupational therapy throughout the day, Osgood explains, rather

than in a separate program. At the core of CTC is Floortime, one-onone, child-directed play periods. In one such session, David, 6, goes down a slide again and again. Each time he reaches the top of the ladder, a teacher playfully blocks his way, leading this very passive child to make eye contact and make his wishes known.

"She wants him to move her hand or say 'Move' and be intentional," explains Lauren Blaszak, CTC's assistant director. "She's got an agenda; he doesn't know it. He keeps going back for more because it's fun." Building social interactions this way, she says, will make it easier for David to join circle games at school and sit at the dinner table at home.

Osgood worked in an ABA program for six years. "It does a great job with skills," she says, "but the kids lacked the ability to think on their feet, to problem solve and to engage socially." She also feels that the ABA emphasis on "looking normal" doesn't address the

reasons for behaviors like flapping and rocking: "Those are organizing strategies to cope with anxiety. Our philosophy is not to say 'Don't do that.' In DIR, we respect them for who they are but give them the tools they need for successful lives." Sometimes literally: Osgood tosses a boy a Koosh ball when he asks for something to fiddle with in his hand. Knowing to ask, she says, is part of learning to regulate oneself.

While Greenspan has published impressive long-term results, his critics say there's an absence of controlled, randomized studies. He is responding with a series of studies just getting under way at York University in Toronto. Among them is work that should help illuminate choices for struggling parents: imaging studies that will compare the brains of DIR kids with those treated with ABA. -With reporting by Amy Lennard Goehner

The Most Difficult Decision of My Life

HEN MY 47-YEAR-OLD HUSBAND Fred lay dying in a hospital from a heart attack, I sobbed to my brother, "He can't die. Who will give Nate his shots?" Nate was our autistic son, then 5, and the injections were one of the myriad can't-miss cures we had tried in order to help him.

My husband died that night seven years ago, and I felt it was the end of the world for me, for our newly adopted 10-week-old son Joey and, most of all, for Nate, whose strongest connection was to Fred.

I learned to inject Nate. And when I decided a few months later that the shots weren't helping him, the decision to stop seeing that doctor (a doctor who had told Fred and me that Nate wasn't autistic and that he could cure him) was the most difficult one I had ever made without Fred.

committed to preparing students for lifelong inclusion in the community, so it sends the kids home, with detailed vacation goals, for eight weeks of the year. That way, they can generalize the lessons they learn in school. Higashi was founded by Dr. Kiyo Kita-

hara, a teacher who believed in searching out the "bud of self-identity" in every autistic child and fostering it with loving care. Her program, Daily Life Therapy, is more like Floortime than like ABA (see "A Tale of Two Schools") but takes its own unique approach. The first step is to get the child to develop a 24-hour rhythm through intense physical exercise. For example, a lot of autistic kids will eat only a few select foods, and many have difficulty sleeping through the night. At Higashi the kids jog twice a day on the theory that come mealtime, they'll be hungry enough to try new foods. And the

endorphins released during exercise reduce anxiety-which is good because Higashi does not permit the use of psychotropic medications.

All that exercise also means the kids are exhausted at the end of the day and tend to sleep through the night. Nate was always fine after he fell asleep, but oh, those endless routines leading up to bedtime! For eight years, he insisted on sleeping in the same red T shirt with a yellow taxi on it, his large toy keyboard piano laid across his chest, his stuffed animal placed on a chair facing him and the radio playing a 24-hour news station. Believing that many autistic

kids can be reached by tapping into their creative abilities, the teachers have nourished Nate's love of sports and music. And he has never seemed happier. I can see his rigidity loosening every time he comes home or I visit him at school. Even Joey has noticed the changes. Nate has always confused the pronouns I and you. One day during Nate's most recent vacation, Joey said to me excitedly, "Did you hear that, Mom? Nate said, 'I want to play' instead of, 'You want to play.' He's becoming unautistic!"

Nate's teacher called me last week. She told me that on the basis of Nate's athletic ability and leadership skills, he had been chosen to represent Higashi at the Special Olympics this summer at Harvard.

I sent Nate to Higashi because I knew he was capable of more. I know exactly what my husband would have quipped: "I can't believe Nate's going to Harvard!" -By Amy Lennard Goehner

LIFE THERAPY: Nate, 12, making connections at the Higashi school

> The most difficult, that is, until I decided two years ago to send Nate to a residential school.

> I enrolled Nate in the Boston Higashi School in Randolph, Mass., because I knew he was now capable of more (though I had no idea what "more" was). After years of day school followed by speech, occupational and behavior therapy, Nate had no master plan connecting everything. And I constantly worried that his ritualistic behaviors—like his insistence on sitting in the same seat in the last row of the city bus and crawling over anyone to get therewere never going to decrease.

> During Nate's first week at Higashi, I got a call from his teacher asking me to send a pair of sneakers with laces. Why does he need laces when there's Velcro?, I wondered. "Because learning to tie shoes is a life skill," his teacher told me. It was an "aha!' moment for me-the first of many. Higashi is

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