

September 12, 2004

## The Lessons of Classroom 506

By LISA BELKIN

### I. First Impressions

It was the first day of school last year, Sept. 8, 2003. The kindergartners were arriving in batches at Classroom 506 at the Manhattan School for Children, on 93rd Street between Amsterdam and Columbus Avenues. The parents of these 5-year-olds said they felt lucky to be taking their children to M.S.C. that morning, lucky to have won the scramble for admission to this sought-after institution -- a public school with particular cachet among artistic, educated Upper West Side families who can't or won't pay for private education.

Only half the class was there that morning; the other students would come later in the day, the better to ease the transition to "big-kid school." Taylor, an African-American girl, was coloring a picture. Evan, one of two blond-haired boys, was playing with blocks. Thomas, one of two motor-impaired, nonverbal children, was in a custom-built wheelchair, his blue eyes wide, his gentle face animated, watching from on high as the others drew and chattered and explored.

Richard Ellenson, Thomas's father, was also there, surveying the room. It was Ellenson who devised this experiment, this attempt to reconfigure a classroom -- and, in some sense, the system around it -- so that his son, who has cerebral palsy, could find a way to fit into a world that often seems to resist him. Ellenson, a wiry man dressed all in black against a room awash in primary colors, was watchful, and what he was noticing was how much more work there was to be done.

"The way the space is set up, there are only four possible places to fit his wheelchair," he said to his wife, Lora, who stood with him. The other children had 16 places to sit, he explained, sweeping his hand past four brand-new tables, each with four child-size chairs. He pointed to a threesome of students sitting at a table, not interacting but at eye level with one another, unlike his son. "They are in a moment when they can become friends," he said. "Thomas is not."

There were other parents watching too. They glanced first at Thomas, then at the little girl next to him, who, though seated in a standard chair, had very little head control and was slumped over her Play-Doh. They noticed that while the class list, posted by the cubbies, had barely a dozen names, a small army of teachers -- including an occupational therapist, a speech therapist, an "augmentative communication" expert and several other aides -- had greeted them at the door. Even those who were arriving as kindergarten parents for the first time could sense that this class was different.

"Inclusion," said Suzanne Blank, the head teacher in Classroom 506. There was a small circle of parents around her, and everyone seemed to be smiling just a bit too broadly as she explained what was going on.

"Inclusion" is the latest in a series of evolving strategies for special-needs education. Though the

definition of the word varies, inclusion, as used by educators, generally means making a child with a disability a full part of the class. Instead of merely placing that child in a standard classroom for part or even most of the day and expecting him to keep up (a strategy often known as "mainstreaming"), inclusion involves rearranging the class -- both the physical space and the curriculum -- to include him. Ideally, once an inclusive classroom is rethought and reconfigured, it will serve clusters of children with special needs, not just one, so that impaired and nonimpaired children can come to see one another as peers. Proponents of inclusion say that it is the best way to prepare all children for the real world; skeptics contend that it too often gives teachers responsibility for impaired students without giving them sufficient training and resources, resulting in children with special needs getting improper attention and children without special needs not getting enough attention -- a poor-quality education for everyone in the class.

When Thomas Ellenson began kindergarten last fall, the New York City school system had more than 1,000 classes that met the definition of inclusion to some degree. But the impaired children in those classes struggled with more manageable problems like learning disabilities and speech impairments. Thomas fell at the serious end of the disability spectrum -- he could not speak or walk or sit unassisted or feed himself. By that distinction alone, Thomas's disabilities made his classroom a first. "There is nothing else like this in the city," Linda Wernikoff, the deputy superintendent for special-education initiatives, who helped create the program, told me. "This is a step beyond for us."

To chronicle a year, as I did, in and around Classroom 506, was to observe the most ambitious step toward inclusion by the largest school system in the country. But the story of Classroom 506 is also something more. It is an extended look at just what it means to be the parent of a special-needs child in the United States right now -- a time when it effectively falls to the most vocal and persistent parents to shape policy and practice. These parents attend workshops, then take what they have learned and educate their children's teachers. They hire experts to write reports and document exactly what their children need. Many quit their jobs so they can have the time to choreograph their children's care. Some go even further and change careers, turning their hard-won expertise into a full-time profession. And at least one set of parents, Thomas's, have gone the distance -- persuading the City of New York to design a classroom and a curriculum to their specifications.

If their experiment were to work, Richard Ellenson said at the outset, it would "provide a template for how to teach children like Thomas so we don't have to recreate the wheel for every child who comes along." And if it were to fail, he said, he and his wife would have no idea how to educate their son.

A mere four months earlier, Classroom 506 was not a possibility for Thomas. In May 2003, he was finishing preschool at a private program called Standing Tall, which served children with severe motor impairments but a wide range of cognitive abilities. The Ellensons, like the parents of preschoolers throughout the city, were determined to find the perfect elementary school for their child. To them, education was everything. Richard is a graduate of Cornell and a founder of the advertising company where he works. Lora, a physician and a scientist, runs a research lab at New York-Presbyterian Hospital. (By way of full disclosure: Richard's mother was my kindergarten teacher, though Richard and I met only when I started to write about him.)

But the longer the Ellensons searched, they said, the more they came to believe that what they wanted for their son did not exist. Thomas did not belong in District 75, the city's classification for programs serving students who are severely disabled, because, they reasoned, he might get lost in a system that included so many children who were cognitively as well as physically impaired. Thomas might be a better fit in a school designed just for children with an array of physical problems, but they feared that

that experience would not prepare him to interact in the real world. And while they could mainstream him into a standard public- or private-school classroom, that would present the opposite problem: he would not interact with anyone else like him.

A solution to the Ellensons' dilemma began to take shape one evening in May of last year when they were the hosts of an end-of-term thank-you dinner for the teachers and therapists who had helped Thomas through preschool. The group gathered at Zoe, a SoHo restaurant, and talked about there being no appropriate place they knew of for the boy to go next. At one point in the evening, all heads turned as Mayor Michael Bloomberg arrived for a dinner of his own. Richard, who has never been described as shy, excused himself and, moments later, returned with the mayor. Bloomberg promised the table that he would help and provided a telephone number. Within the month, Richard was meeting with Dennis Walcott, the deputy mayor for policy, and with Wernikoff, sketching plans for a kindergarten class that would include three or four children like Thomas.

Such a classroom would not be cheap. The law requires that a district pay for needed services for special-education students wherever they are schooled; during his last year in private preschool, for instance, Thomas cost the city \$40,000 in supplemental services. Therefore, many of the costs -- for physical, occupational and speech therapy -- would be accrued by the district whether it created this class or not. And the argument could even be made -- and the Ellensons certainly made it -- that the long-term cost would be lowered because so many children at one site would centralize the work of the therapists. That said, it would still be more expensive to educate the 18 children who would be in this class than it would the 25 students in the school's largest kindergarten class. It would cost \$35,000 more, Wernikoff said.

Because they were involved in the planning, the Ellensons knew exactly what awaited their child on the first day of school, while the other parents in the room were taken by surprise. There had been no announcement, no meeting, no letter home. Susan Rappaport, the crisp and polished principal of the Manhattan School for Children, had insisted on that. "We wouldn't warn parents that there would be African-American children in the class or children who need glasses," she told me before the program began. "If they believe their child should not be in this class, then I believe their child is not a good fit for this school."

No parent objected that first morning. They smiled. And they watched. Kate's mother beamed when her daughter showed off a star she had drawn. Daniel's parents gave him a hug after he put his toys away. Thomas's parents grinned nervously when they met Thomas Parham -- who immediately became known as Big Thomas -- the muscular, impeccably dressed "para" (classroom-speak for paraprofessional) who would be their son's aide every day of the school year.

The morning ended with circle time. Big Thomas wheeled his new charge to a spot on the rug. At one point, as the teachers read a story, Thomas looked back at his mother, then down at his wheelchair tray, then toward the door and then back toward his mother again. His para didn't know how to read his message, but Lora did. "He has to use the bathroom," she said, and sped over to take him there.

When the story was finished, and Thomas had returned, the teachers taught the children a getting-to-know-you kind of song. At the end of each stanza there came a pause designed for a child to say his name, which was then sung by the entire class. "Annaliese," Annaliese said shyly. "Evan," Evan trilled. "Taylor," Taylor sang, bouncing.

Richard saw the awkward moment looming and raced over to Thomas's wheelchair to dig out an electronic device from the storage pouch in the back. He was frantically trying to turn it on and show

Thomas the button that would cause the machine to speak his name when the teacher pointed their way. She could see that they were not ready, but she had no choice -- she had saved Thomas for last, and the song was about to end. Thomas tried to do his part, and pushed the button, but his attempt resulted in silence.

Flailing a little, he tried again. A deep, mechanical male voice, completely out of rhythm, said: "Hel-lo. My. Name. Is. Tho-mas."

Thomas grinned in victory. Richard tightened his jaw in defeat.

## II. Learning to Advocate

The Ellensons' sleek three-bedroom apartment on the Upper East Side has no hallways and few interior walls. Every space is wide enough for a wheelchair to maneuver in easily, and if you stand in the living room, the kitchen, the dining area or the TV room, you can see into nearly every other room in the loftlike home. This way, Thomas, who cannot motor on his own, is never left behind. The Ellensons gutted the space and redesigned it five years ago. Becoming the parent of any child means figuratively reconstructing a life with the child at the center. Becoming the parent of a handicapped child means literally doing so, too.

Thomas was the Ellensons' firstborn. (Their daughter, Taite, who is "typically developing" -- a phrase that parents and educators in this language-sensitive world prefer to "normal" -- is 2.) Until Thomas's birth, in September 1997, they knew virtually nothing about educational theory and practice for the disabled or about recent changes in the law and society that offer equal parts opportunity and frustration for the parents of children with special needs. Those changes began nearly 30 years ago, with the passage, in 1975, of federal legislation that has come to be called the Individuals With Disabilities Education Act, or I.D.E.A. Echoing the language of civil rights law, it required public schools to provide free education that met the special needs of students with disabilities. In practice, this resulted in the creation of separate classes, programs and even school wings for children with disabilities, who were then "mainstreamed" with their able-bodied peers at lunch or for music and occasionally for some academic lessons.

In the 90's, the legal backdrop changed again. Further amendments and court interpretations of I.D.E.A. required that disabled children be guaranteed the "least restrictive environment" in which they can learn. This has been taken to mean that a child will be placed in a general classroom unless the school district can document that educating that child would be impossible in that classroom even with "supplementary aids and services," which the courts have defined broadly.

Notably absent over the years from these laws and interpretations has been financing. The states receive some federal funds but must provide the rest of the resources themselves, sharing that responsibility with individual school districts according to complex formulas that vary in detail from place to place. Few districts have gone knocking on the doors of disabled children to offer a long list of expensive educational options. The effective outcome has been to place the onus largely on the shoulders of the parents. Across the country, the more vocal the parent, the more accommodating the school.

In the years since Thomas was deprived of oxygen at birth, resulting in cerebral palsy, the Ellensons have learned how to advocate. They have come to understand that "the law says we have to be heard," as Richard explained when we met at the opening of school. More important, though, the Ellensons have learned that the provisions of I.D.E.A. have to be reauthorized every five years and that Congress has yet to agree on the latest reauthorization. In other words, their protections are not guaranteed.

From his first meeting with Wernikoff, Richard Ellenson stressed that his crusade was not merely about his child in this school this year. He and Lora are aware that they have been heard not only because they are articulate and untiring but also because they have resources and connections. And they said they feel a responsibility to children whose parents do not have those things. "We are not here just to build a good classroom," he said. "We are here to build a program that can be recreated."

In June 2003, Wernikoff and Ellenson set out to find a school that could be home to Thomas's new classroom. Ellenson, who never met anyone whose contact information he didn't keep, spread the word and received a suggestion from a lawyer named Tucker McCrady, whose daughter, Valente, was a fragile but spunky girl a year older than Thomas. Like Thomas, she was nonverbal and barely mobile but bright. Unlike Thomas, she suffered from a seizure disorder, which came on often and without warning.

Valente had just completed kindergarten at the Manhattan School for Children. M.S.C. was founded in 1992 as part of the "small schools" movement, which brought about the subdivision of many large city public-school buildings into more manageable spaces. As a kindergartner, Valente was the only disabled child in her grade and up to that point, according to Susan Rappaport, the principal, "the most challenging student we had worked with." Rappaport said that the school had not given Valente all she needed during her kindergarten year because though "we had people who were very good and worked very hard, we didn't have the support system." And it was not only Valente who needed more -- more time with outside therapists, more classroom equipment adapted to her needs. The little girl's teachers needed more as well. "They needed training and also moral support," Rappaport said. "They needed to be part of a team instead of out there on their own."

When Rappaport met with Ellenson, she told him she was eager to help. Together with Wernikoff, they decided that there should be two classrooms. Each class would be team-taught by two teachers -- one with experience in kindergarten, the other with training in special ed. Having two classes would not only give the teachers an empathetic sounding board across the hall but also prevent the inclusive classroom from being stigmatized as the "special ed" classroom. The McCradys said they felt that this arrangement would benefit Valente and decided, for this and other reasons, to have her repeat kindergarten in one of those classes.

Before long, two classrooms at M.S.C. were reserved for the program that Ellenson, ever the adman, branded "MotorVation." They would be standard classrooms filled with adaptive furniture and wide aisles. A third, a small activity room, was also set aside for the children in the MotorVation program. It was called the Blue Sky Room, so two parents painted its walls a shimmery blue with puffy white clouds. Rather than pull the disabled children out of lessons to have physical therapy by themselves, the entire class could have organized exercises together in this room -- treatment masquerading as fun.

The teachers were chosen by mid-July of last year. Alysa Essensfeld and Tracy Chiou would teach in Classroom 503, which would be Valente's class. Across the hall, in Classroom 506, would be Suzanne Blank, whose calm yet energetic manner had led M.S.C. kindergartners to fall in love with her for the five years she had been there, and Brooke Barr, who was new to M.S.C. but jumped at the chance to help initiate the program. Barr became a special-education teacher because her son, Matthew, who is now 12, was found to have severe autism. Classroom 506 is the kind of environment, she told me, that she wished her own child could be in.

There were two other disabled children signed up in Valente's class -- one who was moderately motor- and speech-impaired and another who had a degenerative bone disease and was learning to use

headgear attached to a special stick to write, paint and draw. Initially, there was just one other disabled child in Thomas's class, but on the second day her mother decided it was not a good fit and chose not to enroll her. That left only Thomas. His father spent a few days feverishly working the phones, and Thomas was soon joined by a boy named Fredy, afflicted with moderate cerebral palsy, and Danielle, who could drive her own motorized wheelchair and move on her own if she walked on her knees.

When the first day of school began and Ellenson looked at what he had started, he saw the seeds of permanent change in special education. But Wernikoff had simpler goals. "We want these kids, all of them, to get high-quality instruction and be truly included," she said. "You can be in the class. It's another thing to be truly part of the class."

### III. Story Time

It was story time in Classroom 506. Suzanne Blank gathered the students on the rug and placed the storybook on an easel up front. This book was not like any she used to teach kindergarten in the same classroom the year before. It was oversize -- each page was two feet wide and two feet high. And the pages were laminated, with two Velcro strips along the bottom. On the top row of Velcro, words were attached forming the text of the story: "Who will help me plant this wheat?" asked the little red hen. "Not I!" said the duck. "Not I!" said the cat. "Not I!" said the dog. On the lower row was a series of pictures that corresponded to the words above. The word "duck" was represented by an image of a duck; the verb "plant" was represented by a hand putting a small plant into the ground.

Children who cannot hear learn sign language. Children who cannot see learn Braille. Children who can hear but not speak, like Thomas, learn their own language too. The symbols used in Classroom 506 are known as Mayer-Johnson symbols -- thousands of little pictures that represent words and actions and thoughts. Long before nonverbal children can write or read, they can recognize symbols that mean "I want" and "milk" and point to them to make themselves understood. Thomas had been immersed in these symbols since he was 1 year old. His wheelchair tray was filled with dozens of them -- ways of saying yes, no, happy, mad, wash, play, eat, drink. His teachers were now using that foundation to teach him to read.

A few days before each storyboarded book was read to the class, it was previewed for Thomas and Danielle, so they could learn the symbols for new words like wheat and hen. Those symbols were added to their Tech/Talk devices -- Tech/Talk being one of a variety of brands of speech technology that let nonverbal children be heard. The Tech/Talk device is a box with a series of squares in which plastic strips with symbols are inserted. For each new book, a teacher would record the spoken word for each symbol into a digital recorder inside the box. So when the class chanted, in unison with the little red hen, "Then I will do it myself," Thomas could press the appropriate button and join in.

Producing these adapted texts was the never-ending job of Carol Goossens, an expert in "augmentative communication" -- the art of providing means of expression to those who cannot speak. She had ambitious plans for helping Thomas when she first began, but as autumn turned to winter last year, it was all Goossens could do to keep up with adapting the books. "Everything about this was more complicated than we'd thought," she said in November. "Even the experts are learning as we go."

One unexpected complication that first term was that Thomas resisted using his personal communication device at school. Long before he started kindergarten, his parents had experimented with a variety of augmentative-communication devices and settled on a Fujitsu Tablet PC as the one he could most effectively use. By the time Thomas arrived at M.S.C., Richard had programmed countless words and phrases into the device. It was the Fujitsu that the family had scrambled to set up on the first

day so that Thomas could "sing" along. By the second day, Ellenson had scanned digital photos of every child in the class into the Fujitsu, and he called them over as they arrived at school to show them that his son could "speak" their name. Once he had their attention, Thomas flipped to another folder in the machine and told his classmate a couple of jokes: What do you call a fairy that doesn't take a bath? Stinkerbell. Why did the cow cross the road? To get to the mooovies.

After a few days in Classroom 506, however, Thomas started insisting that the device be kept out of sight. He wasn't much happier with the Tech/Talk that his teachers had prepared for story time, which meant that he could not really participate in class. His father could not understand Thomas's resistance, but Goossens said she thought the reason was clear. "The device came with the risk that he would hit the wrong button and say something wrong," she told me. While he was willing to take that risk in front of his parents, she speculated, "he didn't want to do it in front of the other kids."

Another early obstacle was deciding where and how Thomas should sit. Seating and positioning children with resistant or spastic muscles is something of an art. "If he could sit cross-legged on the floor and use his hands, it would change his life," Lora said. But he can't, and deciding where he should sit always involved a tradeoff. His custom-built wheelchair provided the support he needed, and gave him his best hand control, but left him several feet above his peers. On the other hand, a series of low-to-the-floor chairs that the school's physical therapists provided for use at story time and for tablework brought him eye level with his peers but caused him to slouch and slump and made it all but impossible for him to use his hands.

Thomas made it clear as the year went on that he wanted to be like the other children. He wanted to sit near the floor, whether he slumped or not, and when his classmates were writing with crayons and pencils, he wanted to use those things, too, even if he could produce only scattered scrawl. In other words, he wanted to sit in the least-supportive place and use the least-efficient tools. Yet becoming more like the other kids in the long term, learning to read and write and communicate, often meant not being like those kids in the short term -- sitting high up so he could write, using letter stamps instead of crayons.

Where Thomas should sit became a constant source of tension between Rappaport, who wanted Thomas to be close to the floor whenever possible, and Ellenson, who thought he belonged in his custom-made wheelchair until a better close-to-the-floor option could be found. Such friction is common between a parent and a principal when the parent becomes a constant, vocal presence in a school, but no less frustrating. "A parent has to be willing to let the school explore," Rappaport said. "That's why the parents partner with schools."

The teachers navigated these clashes as best they could, tending to sit Thomas on the floor for circle time but in his chair for most other activities. Barr, for one, said that she believed that Thomas needed fewer choices and began to act on that belief. "It's what I call my British-nanny persona," she said. "It's not, 'Would you like to go to the park?' It's, 'Off we go to the park!'" Slowly the approach worked. Thomas took what was offered and even started warming to his communication devices again.

Barr began helping Thomas write stories on the classroom computer. Using special software and a track ball, he could click on the Mayer-Johnson symbols for "my" and "sister." But the computer, while liberating, was also frustrating. By necessity, Barr limited what Thomas could write about, because she had to enter the available symbols in advance. And his use of the track ball was spotty, so the results were sometimes less than perfect.

One November morning, Thomas, working one-on-one with Barr, had painstakingly entered "My sister

Taite" on the computer screen. Asked to choose his next word, he clicked on "a lot."

"What does she do a lot?" Barr asked, not at all sure if the word was purposeful or random.

"Runs talks falls falls hugs," Thomas typed by clicking the matching symbols. As each word appeared on the screen, the computerized voice spoke it aloud.

Barr had certainly seen children write stories that made little sense, but she suspected that Thomas was actually trying to say something succinct. The whole exercise was like working a Ouija board -- was she helping him write what he meant or what she thought he meant? "Um, let's try that again," she said. "What does Taite do a lot? Does she run a lot? Hug a lot?"

"Falls hugs falls talks runs," Thomas wrote.

"O.K.," Barr said when it became clear that Thomas's energy for this task was spent. "Let's print this out and read it together."

Children in kindergarten at M.S.C. turned their stories into "books" by adding "covers." So a short while later Thomas was in his wheel-chair with a piece of construction paper taped to his tray and the

alphabet arrayed in front of him in the form of 26 small rubber stamps.

"What's the first sound of 'By'?" Barr asked. "Buh. Do you see it?" Thomas's hands moved everywhere but to the B. He put his face nose distance from the tray, searching for the answer. As he did, his flailing hand landed in the inky stamp pad.

Sensing his frustration, Barr handed him the letter B, and he pushed the stamp onto the paper. "Great job," Barr said. "Now how about the next sound. 'By-ayyyyye.'" Thomas glanced back over his shoulder. At first it looked like a random motion, but when he did it a second time, Barr followed his gaze. He was looking toward the basket of books that students had already finished. "Oh, you want to look at what you've already written -- good strategy," she said. She brought over a previous effort, done just as painstakingly on another day. Seeing that the letter he wanted was Y, he pointed right to it on his tray.

The teacher's smile was nearly as wide as the student's. "Now, who's this story by?" she asked. "Who wrote this story?" The boy's hand went shakily, but deliberately, over to the T. Then the O. Then the M. Barr handed him each stamp, and he made a blurry impression. "BY TOM."

#### IV. Making Friends

One morning near the start of the school year, Blank took Ellenson aside when he brought Thomas to class. The other children were asking questions about Thomas, she told him, and they stared at the boy more often than they talked to him. Blank knew that Ellenson had spent a lot of time explaining his son to other children, and that he had volunteered to do the same for his son's class, if necessary. She said she thought it might be necessary.

Ellenson agreed, but said he did not want to be the only parent to talk about his child. "If the message is that every child is an individual, then we have to talk about another child or we're singling Thomas out," he said. The following Friday, Ellenson arrived for morning circle time to "share" about Thomas, and another father, Stephen Lee Anderson, came to "share" about his son Evan.



At the center of the Ellensons' dreams for Thomas is the hope that he will make friends. It is one of the few pieces they can envision with any clarity in the puzzle that will shape itself into his life. They think he is smart, but they understand that a parent's lens can be cloudy on that subject, and they also know that it is hard to test a child who cannot speak. If he is smart, they are sustained by visions of Stephen Hawking, who has changed the world of physics despite being trapped in a body that is little more than a container for his brain.

And they think Thomas may have other gifts too. His favorite television channel is the Food Network. One of the handful of words he can physically speak with relative clarity is "Emeril," the name of his favorite chef. He loves to help his parents in the kitchen. A chef can direct without doing, his father says, and a sophisticated palate is within the realm of the possible for Thomas. If he does harbor talent, then the Ellensons' hopes are buoyed by their friend Dan Keplinger, known to the art world as King Gimp, the subject of an Academy Award-winning documentary about how he paints, using a paintbrush on a headstick, despite his cerebral palsy.

But even if Thomas's future doesn't hold such creative or intellectual promise, he will need friends. He lights up when other children are around. He craves interaction, thrives among other people. Equipping him for this part of his life was one reason -- as important as teaching him to read and write -- that his parents fought for this class. They know that socialization gets only harder as disabled children get older.

Starting down that road was Richard Ellenson's goal when he stood at the front of the class, alongside Thomas, on the second Friday of school. I was not there that morning, but Ellenson, Anderson, Barr and Blank were all moved by the visit and described it to me in the same way.

"We want to talk about something that's very important in our family," Ellenson began. "Thomas has cerebral palsy. Does anyone know what that is?"

The children shook their heads.

"Thomas's brain got hurt when he was born," Ellenson continued. "Because of that, Tom can't actually speak, and he has to be in a wheelchair. But other than that, he understands everything we say. Right, Tom?"

Thomas smiled and looked up toward the ceiling.

"Thomas speaks in his own way," Ellenson went on. "Isn't that right, Tom?"

Again the boy raised his eyes.

"When Thomas wants to say yes, he looks up," Ellenson explained. "Does everybody else want to try that?"

The children looked up. Then Thomas and his father taught them how to say no -- by putting their heads down.

"Everything we're doing, he's doing," Ellenson said. "It's just that he does it all inside his head." He paused. "Any questions?"

Connor raised his hand. "Can Thomas swim?" he asked.

Ellenson said he could, then showed the children how. He lifted the boy out of his chair, and Thomas put his arms around his father's shoulders. Then Ellenson got on his knees and walked around, the way he and Thomas do in the shallow end of a pool.

The children giggled. Connor raised his hand again. "What color bathing suit does he wear?" he asked. "Does he wear water wings? I wear water wings." Soon afterward, Anderson talked about how he and Evan do puzzles together on Sunday mornings. That, Ellenson told me, was when he thought, It's going to be O.K.

And in many ways, it was O.K. A few days after the fathers came to share, Thomas's classmate Taylor broke the ice. She wanted to sit next to Thomas in circle time and push his wheelchair to the table at lunch. "If I ever need a wheelchair, I want one just like Thomas's," she told the class, and soon everyone wanted to try out his chair and be pushed around the room.

Evan also developed protective feelings toward Thomas, and within a few weeks he was giving voice to what Thomas wanted to say. The others recognized the depth of their friendship. One day, Ellenson watched as his son tried to make himself understood to another classmate, a little boy who was never completely comfortable around Thomas. "Evan will be here in a minute," the boy said. "Evan always knows what Thomas wants."

Richard and Lora tried to help by making new friends of their own. The more they could include Thomas's classmates' parents in his world, they argued, the better life would be for Thomas. The surprise expressed by the other parents on the first day of school had turned into varying degrees of warmth. Some, particularly Evan's parents and Taylor's, developed real affection for Thomas and brought their children over to play at his house. Others never really got to know the boy but made their peace with this experiment when they realized that the small size of the class meant that their own children got more attention from the teachers than they would in a regular classroom.

Each time he visited Classroom 506, Ellenson scanned the class for social moments for Thomas. When he couldn't find any, he created some. One day, he arrived at the playground during recess and saw Thomas sitting alone in his chair while the other children ran and played. So Ellenson became the Pied Piper and created an obstacle course, with Thomas stationed as one of the hands to be high-fived as each runner reached the finish line. His message seemed to have taken. A few days later, Thomas could be found beneath the slide, next to the play steering wheel. He was the bus driver. Big Thomas took out a MetroCard, and the other children took turns getting on the bus and telling their driver where they wanted to go.

Birthday parties, too, looked different to the Ellensons. "The minute we walk into a party," Lora said, "we're thinking, How can we make Thomas part of this world?"

When Kate had a soccer party at the Chelsea Piers sports-and-entertainment complex, Richard tried to hint to the athletic 20-something in charge that maybe Thomas could be "official scorekeeper." But the suggestion was ignored, and Thomas sat on the sidelines, his father crouched alongside. When a ball came their way, Ellenson scooped it up and placed it in Thomas's lap, then helped roll it down his legs and onto the field. "I'm not sure it kills him," Ellenson said of his son, "but it really kills me."

A week later, at a party for Taylor, the bowling alley supplied an adaptive device for wheelchairs: an orange metal contraption that looked like a walker but with a ramp attached, sloping down from the top of the device to the floor. Thomas could push the ball down the ramp and watch it roll toward the pins. Evan, who was Thomas's teammate, thought this was a nifty way to bowl, and soon he was using the

apparatus too. By the end of the party, children all over the bowling alley, even those who happened to be there for other birthdays, were pushing their bowling balls down the slide.

## V. Frustrations and Breakthroughs

By early spring, Ellenson was frustrated. On the one hand, he was grateful to Rappaport, and Wernikoff, and the mayor, and to everyone else who had made the program possible. On the other hand, nothing was as fast or as complete or as ambitious as he knew it could be. Lora, who worked in the incremental world of science, accepted that progress was often slow. But Richard was in advertising, and to him, if something was slow, it wasn't progress.

"Where I come from, you have a deadline, and you stay up all night, and you meet it," he told me on one of his frustrated days. "I thought everyone would be working nights and weekends on this."

He was grateful for the Blue Sky Room, which was designed and equipped in just a few weeks. But he was disappointed that it was used as much for an ordinary therapy room as for whimsical activities for the entire class. "Have yoga every day," he said. "From a marketing point of view, that would make parents choose this over Dalton."

He liked that Thomas's teachers had started preserving tidbits of each day's class into a digital recorder so that when Thomas came home he could answer the question "What did you do at school today?" But Richard was also frustrated that so many good ideas that had been used before, by other parents in other schools, hadn't been widely shared. He learned at a conference that another family had thought of using a recorder in the same way for their child a year earlier: how many more days of conversation could he have had with Thomas had he known?

Ellenson was still baffled that an effective low-to-the-ground seating option could not be found for Thomas. And he said that he felt similarly stymied that while Goossens, the augmentative-communication expert, was hired to devise an array of opportunities so Thomas could communicate -- like programming a Tech/Talk with vocabulary versatile enough to discuss everything from cookies and milk to the relative merits of building Lego airplanes and trucks -- much of her time was being spent adapting books. He worried that Thomas's own "voice" was rarely being heard.

What seemed to trouble Ellenson most of all was that, as he saw it, others didn't share his urgency to create a reproducible template for future classes. To his mind, the entire effort was wasted if it did not result in a program that was a model not only for schools in the district but also for others throughout the country. "At the end of all this," he said, "we should have a packet we can hand to the next team and say: 'This is what works; this is what doesn't. You don't have to start from scratch.'"

The teachers and administrators were not so sure. "Children are too different," a therapist told him during one of many conversations that bordered on arguments. "You can't write a recipe book for a classroom."

"If you had to build a new bridge every time you reached the East River," Ellenson replied, "no one would ever get to Brooklyn."

Lora gently prodded her husband to focus on the progress amid the obstacles, and when he looked, it was certainly there to see. Thomas was thriving, Richard knew, and it was because of steps he and his wife had taken. Several months into the year, for instance, Richard had introduced the M.S.C. team to Pati King-DeBaun, an expert in teaching reading and writing to nonverbal children. Her energy was

infectious, and Ellenson wanted her aboard, but Wernikoff worried that it might take months for her to be paid through city channels. So Ellenson paid her consulting fee himself, hoping that he would be reimbursed eventually. In all, he laid out about \$15,000 last year filling what he saw as gaps in the program. He did this not only for Thomas, he said, but also because he felt a responsibility to the other students enrolled in the program he started. "Had Lora and I not been willing to spend the money," he said, "then I would be asking six other children to come along with Thomas on a ride to nowhere."

King-DeBaun flew in from her home in Utah about once a month. During her visits, she held workshops on specific issues of literacy training but imparted more sweeping lessons as well, like how to view learning through Thomas's eyes. "She changed everything," Barr said. "I had a lot of tools. She taught me how to use them."

One of King-DeBaun's insights was that children typically learn to write before they really learn to read. And one way they learn to write is by speaking. They feel sounds in their mouths, trying them out, rolling them around, and then they come to picture those sounds as letters and words. Children who cannot speak must be helped to hear their own voices in their heads, she said, because that voice, though silent to onlookers, was definitely there. This lesson proved to be the key to more than just teaching Thomas to read. It transformed the way Thomas was seen, not only by his teachers, but also by his parents.

This change did not occur in a single moment, but in tiny increments over many months. It was most evident in the sign-in books the children used every morning. The books were the idea of King-DeBaun, who said that each child should start the day by expressing himself in whatever way he chose. There was no right or wrong way to fill the day's page in the individual books, and while the other children drew pictures or wrote stories, Thomas used stamps at first, then started asking for a crayon. Slowly his scattered scrawls became loose interpretations of letters. By spring he was determined to write his name.

To his parents, Thomas's sign-in book was a window onto his inner life. "He's thinking what the other kids are thinking -- he just doesn't have a way to express it," King-DeBaun assured them, and while they hoped that was true, it was not always easy to believe. One day, for instance, Thomas was in his bedroom, and his father pointed to the bookcase and asked how many books were on the shelf. "Eleven," Thomas answered, correctly and without hesitation, by pointing to the numbers on his tray. Richard found himself thinking, Does he really know that, or was that just luck? A short time later, Richard asked, "How many children are in your class?" Again, without hesitation, Thomas answered, "Seventeen." Again Richard wondered if that was an accident.

"Of course a 6-year-old can count to 17," he said later. "But every age-appropriate accomplishment that Thomas has comes as a surprise. That's a shame."

If Richard could not see the whole of Thomas, how could his teachers be expected to? Following King-DeBaun's lead, Ellenson prodded Thomas one evening. The boy had just pointed to the symbols for "Thomas," "Natalie," "wash." Ellenson understood that he wanted Natalie, his home health aide, to give him a bath.

"When you point to 'Tom,' 'Natalie' and 'wash,'" Ellenson asked, "what do you hear in your head?" Ellenson held out one palm toward his son as he said, "Does your head hear 'Tom. Natalie. Wash'?" Then Ellenson held out the other palm. "Or does your head hear something like, 'I want Natalie to give me a bath'?" Thomas pointed toward the second palm.

Ellenson tried again. "When you said, 'Taylor ball pink' this afternoon, did you hear: 'Taylor. Ball. Pink'? Or something like, 'I want Taylor to bring me the pink ball?'" Again Thomas chose the full sentence.

Over and over, Ellenson asked, and over and over his son gave the same answer. In his head, he was letting his father know, he spoke just as fully and completely as anyone else did.

## VI. 'Do You Know About Valente?'

Across the hall from Thomas, in Classroom 503, Valente McCrady was falling behind. The year before, when she was in kindergarten for the first time, "she was a sponge," her father said, "learning her letters and solidifying her colors." Her goal for this repeat year, she had told her teachers, was to learn numbers. But as winter turned to spring she seemed to be losing ground.

Her parents were in the unique position of seeing firsthand how MotorVation changed the way the same child was taught in the same grade, and they knew that Valente was stalled not for want of effort from her teachers. During her first year in kindergarten, her father said, the staff always seemed to be "playing catch up -- preparing a lesson and then scrambling at the last minute to adapt it for Valente." During the second year, by contrast, he saw them "beginning to plan the activity itself around Valente."

Her lethargy was not a result of unhappiness, either. She loved being with other children, particularly "typical" children, her father said, and that was why the McCradys had placed her in the Manhattan School in the first place. The reason she was failing was physical. Her seizures were coming more often, leaving her limp and exhausted. Her motor skills declined. "At the start of the year she was a demon with technology," Goossens said. But as the months went by "we were picking up her arm, putting her hand on the button and saying, 'C'mon, honey, can you just press it?'"

Her doctors tried new medications. Her parents consented to brain surgery. Then, in February, just before the operation was scheduled, the McCradys heard about a diet designed to bathe the brain in fat. For every gram of carbohydrate or protein Valente ate, she would eat four times as much fat. Her food was slathered in butter, margarine, olive oil, mayonnaise and heavy cream.

Her teachers and paras learned a lot about fats and proteins. They knew that a small misstep could throw the girl into seizures. "We weren't worried about them messing up because they were as scared as we were," McCrady said.

For several weeks she became bubbly and attentive. She had a growth spurt. She began learning. As quickly as the improvement started, however, some worrisome signs reappeared. Valente started having seizures again. One morning she suffered four of them before 11 o'clock. "That poor little body, how much can it take?" Rappaport wondered.

The answer was not much more. On Thursday, April 22, Valente died at home, in her sleep.

Rappaport learned of Valente's death the next morning and called the kindergarten and first-grade teachers in, a few at a time, to tell them. "That little girl was a very, very important part of the foundation of this school," she told me. "Last year we had nothing to offer her but love and support, and that grew into what you see now."

Soon afterward, Rappaport went from one classroom to the next to be there as the teachers broke the news to their students. As she walked toward Classroom 506, she found Chan Mohammed, Thomas's

baby sitter, frantically pushing Thomas out the door, so he would not hear about what happened. Mohammed called Ellenson to ask if Thomas should stay to listen. "Yes, absolutely, bring him back in there," Ellenson said, though he later confessed that he was not certain it was the right answer.

Soon the children were gathered on the rug with their teachers. Thomas was on one side of the group, Danielle on the other. Both were high in their wheelchairs, Rappaport noticed, when they should have been down on the floor, but she didn't say anything about it. The other adults were standing behind the children, separated from them by a bookcase. That message was wrong, too, Rappaport noted later, but she didn't say anything about that, either.

Blank, the head teacher in Classroom 506, sat on a low chair at the front of the group. "Valente was sick," she said, explaining in simple language what a seizure disorder was and that Valente had died. "Some of you are going to feel different kinds of feelings," she continued. "Whatever you are feeling is O.K."

Taylor crawled into Blank's lap and began to cry.

Rappaport patrolled her building all day, burdened by new knowledge. "This is one thing I had never thought of," she said. "That you bring in this new group and medically they are much more fragile. I thought about this program in terms of the mechanics: where do you seat the child, how do you toilet the child, how do you feed them? But I never thought about losing them."

That night, when they were alone at bedtime, Lora talked to Thomas. "Do you know about Valente?" Thomas looked up to say yes. "Where is she?" Thomas looked way up, past yes, toward heaven, a concept he learned a year earlier, back when Richard lost both parents within three weeks.

"Valente had a sickness called seizures, and you don't," Lora said. "Are you scared?" she asked. Thomas said yes.

## VII. Making Plans

Each year, the kindergarten teachers at the Manhattan School for Children choose a theme and build the curriculum around it. When Thomas was in kindergarten, the theme was bread. From late fall through early summer the students read stories about baking it, did math lessons about buying it, visited a local bakery on a field trip and even performed an adaptation of "The Little Red Hen," who bakes a loaf herself when none of her fellow farm animals will help. Thomas played a duck. His Tech/Talk was programmed to say "Quack, quack, quack."

At the end of the school year, all four kindergarten classes at M.S.C., those with children in wheelchairs and those without, created a bakery of their own. For two weeks beforehand, they baked — banana bread, pumpkin bread, chocolate-chip cookies, chocolate cake, cupcakes, cinnamon rolls — then stored their goods in a freezer. They drew a big sign that said "Madison Square Bakery" and smaller ones that priced the items at multiples of 10 cents each. They spent arts-and-crafts time making placemats and baker's hats and vases with paper flowers.

As the "customers" — the parents — arrived, Thomas was positioned right at the classroom door, near the muffins. His love-hate relationship with his Tech/Talk was pure love that day, and he grinned at anyone close enough to hear him. If you were just out of range, he gestured wildly until you came near.

"Can I help you?" he said. "We made that fresh. It costs 10 cents. Thanks for coming." Barr, his special-

ed teacher, had programmed the device, and it was two of his classmates whose voices actually spoke the words, but from the expression of joy on his face, the words seemed to come from deep inside Thomas.

By the time the Ellensons arrived, there was already a crowd. "Can I help you?" Thomas asked them. Richard began to cry.

The end of the year was the usual blur. Richard Ellenson was elected president of M.S.C.'s parents association. Thomas, who was eager to get to his sign-in book every morning, could now write his name legibly and boldly in crayon. He also gained new mastery of the computer. One of his last projects was an alphabet book filled with animals, and he made it clear that he wanted to sound out the spellings of the words, just like the other children, rather than choose words from a prefabricated list. "Q IS FOR QUJAXL" he typed under a photograph of a quail. "R IS FOR RA!EBBIT." "S IS FOR SKUFNK." Barr was gleeful. "That's the way a kindergartener should be writing," she said.

At an end-of-year meeting, Ellenson and the M.S.C. staff members found themselves talking about the same things they were talking about at the beginning of the year. But now they spoke like veterans, not first-timers. Ellenson expressed his frustration that there still was nothing tangible -- no booklet, no instructions -- to hand down to others who might want to start a similar program. Wernikoff offered more support -- more money, more staff development -- for the coming year and told Ellenson that the school district would in fact reimburse him for the \$15,000 he spent from his own pocket. Rappaport said she was determined to find a low-to-the-ground chair that would facilitate Thomas's use of his hands.

For the coming school year, they agreed, there would again be two MotorVation classes in kindergarten, each with four disabled students. Rappaport knew she could fill those eight slots, because word was out and parents were inquiring. In the first grade, Thomas's grade, there would be only one MotorVation class, taught by Barr and Blank. It would include the motor-impaired children who attended the first year, along with 14 nonimpaired children. All summer the parents of Thomas's kindergarten classmates waited to learn which of their children would be allowed to move up with him into what was now considered a very desirable class.

Thomas Ellenson will start first grade tomorrow morning, in Classroom 406, down on the first-grade floor. He is excited because his best friend, Evan, will be there too.

*Lisa Belkin, a contributing writer for the magazine, last wrote about attention-deficit disorder in adults.*

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