

EDUCATION

Slow-Motion Miracle: One Boy's Journey Out of Autism's Grasp

By JOHN O'NEIL

Six years ago, my son James fell down a well, and he's still climbing out.

James has autism. He is one of 150,000 or more American children classified in the last decade as having the once-rare disorder, including 25,000 in 2003. Half a century ago, polio epidemics left perhaps 5,000 children a year with some degree of disability, and the sight of children stricken overnight galvanized the nation. But autism's arrival, and the response to it, has not been so dramatic.

In James's case, a bubbling 2-year-old who loved "mashed potatoes" and sword-fighting faded away. In his place was a nearly silent, unhappy child who repeated meaningless phrases, lay on the floor squinting or pulled cowboy boots on and off until his feet were raw. Every day he fell a little further out of the world.

But one recent afternoon James sat at our kitchen table with his best friend, Larry, goofing off instead of doing homework. They made dumb jokes and gossiped about their "girlfriends" at their school, just up the street.

It's hard for me to explain how many dreams-come-true are reflected in that one sentence.

James's journey is by no means over. He still has significant problems with reading comprehension, math, attention and social skills. He gets stuck on favorite subjects — though this year, the Yankees, thankfully, replaced the War of 1812. He can sound as if he is speaking a second language, with the halts and mangling of idioms that implies. With his peers, he hovers at the border of acceptance.

would be getting 10 hours of one-on-one therapy a week, instead of the 30 to 40 hours a week called for. We were told that quality was what counted, not quantity. We also knew we had few options.

On the way home, Marcia, a physician, seethed. "Do you think I prescribe half the appropriate dose of antibiotics?" she demanded. But James needed help, and the clock was ticking.

To get James more help, Marcia took him to a private speech therapist. She learned something about A.B.A. that day, but also about how little we knew about what was going on inside his head. She learned, for instance, that James had forgotten his name.

"What's your name?" asked the therapist, Kathy Rooney.

Silence.

"What's your NAA-aaame," she chanted in a singsong. "JAMES o-NEEE-il."

After a few more times, she repeated the question. After a pause, he answered, and Kathy showered him with praise.

The "analysis" in A.B.A. means figuring out what a child needs to learn, the best way to teach it — and whether it's actually learned. The behavioral part means rewarding desired behavior.

In some ways, that sounded like a more rigorous version of ordinary parental tasks, and Marcia began to introduce bits of it, like giving James milk only when he said "milk" instead of just pointing. I was taking him to the pool a lot, mostly to wear him out, since he had trouble sleeping. James loved to jump in, and I tried taking advantage of that desire to perform what I'd later learn was "discrete trial instruction." I held up one finger and said, "How many? One!" If James



Richard Perry/The New York Times

James O'Neil, 8, who has autism, with his best friend, Larry Pan. One sign of James's progress: sharing dumb jokes.

We contacted the parents of the other children in the program, and found they were also concerned. Together, we went to the district's special education director, asking her to let an outside expert make suggestions. But as the director talked about the many costs the districts was facing, the tears trickling down one mother's cheeks dried up. We all got the message: They may be your children, but this is our program.

finding someone to get us started: John Hampel of the Rutgers Autism Program, whom we had contacted when we thought the district might like an expert's help.

He had high hopes, which he expressed in an unsettling way. "James is the kind of kid who is the scariest to work with," he said, "because you never know if you're going fast enough to keep up with his potential."

What followed was an isolating time for

never stop. In the end, the court sided with the first family to go to trial in our district. The creation of district-run autism programs clearly needs to be encouraged, the judge wrote, "but it cannot be at the expense of a little boy."

For the next year we were on the on-ramp to real school in a blur of preparation. But kindergarten turned out to be an anticlimax. He was accompanied by one of his home in-

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But even that list of problems is a sign of how far he has come. Six years ago, he couldn't engage with the world around him.

Scientists know little about autism. What they have learned has underscored the complexity of its genetics and anatomical abnormalities, which begin developing soon after conception. They do know a lot, however, about what to do about autism, enough that a federal panel has set a 10-year target of preventing 25 percent of new cases. The panel's plan faces huge obstacles, starting with an absence of additional funds to carry it out. But the hardest part, panel members said, is making use of what we already can do.

In that sense, James's progress has a sadder side: that he has been such an exception. Not everybody who gets the treatment he did progresses so far, although some go further. But only a relative handful of children with autism are thought to receive even the minimum standard of care, a pattern reflected in an increase in requests for institutional placements as the leading edge of last decade's cases reaches adolescence.

The other key to improved outcomes is early detection. Most cases are caught much later than they could have been, and in that sense James was no exception. Had we any idea what to look for, we could have known in James's first year of life, I think.

James was an easy baby. But looking back, part of the easiness was a lack of intensity in his connection to us. There was some difficulty in meeting our gaze, and a lack of curiosity about things pointed out to him — both hallmarks of autism, and red flags on formal developmental screenings. James never got one, perhaps because his sunny disposition obscured such flaws, and because we were never worried enough to raise any concerns with his pediatrician.

"When he was 2½, we moved to northern New Jersey six weeks after our youngest son, Miles, was born. When James's behavior started to become a bit odd, we just figured he was overwhelmed.

It took a third party to force us to focus on him. The director of James's new preschool took my wife, Marcia, aside one day. "He just seems a little off to me," Maureen, the director, said. "Sometimes he seems not to hear me."

We know now that she was worried about more than his hearing. In the first of many strokes of luck, she was familiar with autism, having taught in a local specialty school. She suggested that we contact the local school district for an evaluation. James

desire to perform what I'd later learn was "discrete trial instruction." I held up one finger and said, "How many? One!" If James said "one," splash! By the end of the week, he was up to three, unprompted.

We began to discover that James is, for a child with his problems, a quick learner when taught in the right way. And not everything had been lost. Shown a hard yellow plastic hat, he answered, slowly but surely, "con-struc-tion hel-met."

But as Marcia began to learn more, her enthusiasm about the happy notes coming home with James began to dim. His teachers seemed to have a hard time motivating him. Most important, he just didn't seem to be learning much.

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Home Program, Tiny Steps

That's how we came to find ourselves sitting in our basement on a stifling July day with strangers who were about to become the most important people in our lives.

When Marcia had first read about "home programs," her reaction had been succinct: "Not for us!" Creating a school for one from scratch seemed insane, even without the lawsuit it would obviously require.

But she had given up her full-time position and done it. Our greatest stroke of luck was



John O'Neil/The New York Times

James when he was 2 years old. A bubbling child, he grew increasingly withdrawn, repeating meaningless phrases, lying on the floor squinting or crying at loud noises.



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What followed was an isolating time for James, at a little table for up to eight hours a day, doing work most children would find tedious in the extreme. Skills normally acquired in a blended rush were introduced in the tiniest of steps. An instructor would place two blocks side by side, one flat, one vertical, say "Do this," and hand them to James. Or touch her nose — "do this" — then her cheek, eyes, brow.

But after a few tantrums it became clear that James liked to work. Not just for the hugs and shiny stickers. He liked being connected. And it was only under this kind of bare, intense focus that he could connect.

Data is the lifeblood of A.B.A.; it is the only way to spot your mistakes. But along with charts of James's trial-by-trial performance, his instructors kept a log of "spontaneous language." On the program's first day there is only one entry: "I want cheese crackers." In August, that starts to creep up, to a half a dozen or so. In late September there is an explosion: "I want a big tickle." "I want the Play-Doh." Another one also jumps out: "Where is Angelica?"

A 4-year-old whose family had just arrived from Poland, Angelica came with her mother several times a week to visit our neighbor. She knew no English and had nothing to do — except try to get James to play. Such a determined child! Angelica was used to a language barrier and was tireless in her efforts to get James into a game, even as simple as one as rolling toy cars down the steps. "Jems. Jems! JEMS!!!"

And it worked. For brief snatches James could play along. James could play!

What was new wasn't just Angelica, of course. James was waking up, thanks to his work at the table. New skills were creating a new interest in the world — which were making other new skills possible.

Now we tried to use our time to extend his learning. I enlisted his brothers, Miles and Chris, to teach simple play scripts, like saying, "Tickets, please!" when the chairs were lined up to make a train. We worked on the countdown for a rocket ride. Chris extended the script: "To the moon! To the stars! AAAAAHHHH!! WE CRASHED!!!"

But every so often there was a fresh bucket of cold water to remind us of how far he had to go — and that time was passing. Like this blunt assessment from a speech pathologist when he turned 4: "Unless his language really picks up, he's not going to make it."

Making it meant placement in a mainstream kindergarten — a crucial sorting point. We went home scared, and Marcia made changes.

kindergarten turned out to be an anticlimax. He was accompanied by one of his home instructors, acting as a "shadow," and yes, things went well, and yes, his problems there were the same ones he had at home, like staying on task and following directions.

What was big in kindergarten was something we hadn't prepared for: Larry.

Sometime during preschool, children had stopped being ghosts for James. But we gradually realized what was developing here was a friendship — the hardest thing for a person with autism at any age.

Larry Pan is enthusiasm with a crew cut. What attracted Larry to James? Perhaps it was James's sense of humor (think diaper jokes). Or maybe they just were drawn to each others' big hearts.

After our rocky start with our district, elementary school has been remarkably smooth. There was one dreadful time in first grade when James suddenly began hitting his aide, raising the prospect that perhaps he could not continue where he was.

The solution turned out to be simple. A swap of aides was arranged, and Jeanette, who had known James since was 3, came in as a backup shadow. She gave him a look and the nonsense stopped. But Marcia and I felt as if we had been swept back to the cliff's edge. When a child falls out of the mainstream, it is hard to return. Unable to sleep, I wondered if this was what post-traumatic stress disorder felt like.

Knowing He Is Different

Nothing like that has happened again. There are still plenty of problems — his progress, in some ways, consists of moving up to a better class of problems. At camp this summer, James didn't know how to handle a boy who was mean; in years past he wouldn't have recognized the hostility. James used to be unnaturally compliant: now his favorite song begins, "You're not the boss of me now..."

And then there's the most painful progress of all: James right now is wrestling with the knowledge that he has autism.

Over the last year, it has become slowly apparent to James that he is different from other children, or at least he is thinking about it. He recently asked Miles, who is now in first grade, why Miles doesn't go to a resource room.

But why tell him?

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As the evaluation process wound on toward his third birthday and James's behavior became more difficult, it became clear that he was not fine. When Maureen called Marcia into her office again, to give a name to our fears — "I think James is a little bit autistic" — it made all too much sense.

Good News, Bad News

A library grew on our bedside table, bearing a message that seemed a sort of good news, bad news joke. The bad news: autism has no cure. The good news: there can be effective treatment. The bad news: it's incredibly expensive, difficult and time-consuming — and nobody wants your child to have it.

So we were pleasantly surprised when we sat down with the school's team and learned the district had recently begun a preschool autism program using the treatment the books recommended, applied behavioral analysis, or A.B.A.

"We had some questions. For one thing, he

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A special section collecting *The Times*'s coverage of autism, including resources for readers and a multimedia feature, can be found at: nytimes.com/health.



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From left, Miles, James and Chris O'Neil playing at home in New Jersey.



Richard Perry/*The New York Times*

Jeanette Murphy, left, one of James O'Neil's after-school instructors, gives him a suggestion during a social skills session built around a play date with Larry Pan, right.

had to go — and that time was passing. Like this blunt assessment from a speech pathologist when he turned 4: "Unless his language really picks up, he's not going to make it."

Making it meant placement in a mainstream kindergarten — a crucial sorting point. We went home scared, and Marcia made changes.

For six weeks, the instructors focused almost entirely on getting James to talk, a lot. One technique was simple. Usually James got treats as a reward for doing well at his programs. For now, all he needed to get them was simply to ask for them.

And it worked. The data the instructors took on requests per hour crept up and up, but in truth we didn't need it. He wouldn't shut up. The intensive effort had jump-started some slumbering connection in the brain. And over months we began to see flashes of a new kind of language — talking that goes back and forth, that changes with each thing that is said.

Then this, from the logbook for April 7, 2000:

Jeanette: I like to eat chicken.

James: I like to eat breakfast.

Jeanette: I like waffles for breakfast.

James: I like cereal for breakfast.

A conversation.*

On the Road to Real School

Also that spring, James returned to the district preschool program we had withdrawn him from the year before. He hadn't been ready for it then; now he was. And so were we: we had reached a settlement in the lawsuit we had filed charging that the district had failed to provide him with an education appropriate to his needs.

That yearlong migraine had drained us of time, emotion and money at a time when we had little enough to spare. But we also felt that if we let the district pound on our child without hitting back, the pounding would

now in first grade, my child would go to a resource room.

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Giving him a name for the difference he is beginning to grasp means letting him begin coping with the issues that will remain after his intervention fades away. It's strange to be thinking of the path to adulthood for a fan of "Ed, Edd n Eddy," the silliest cartoon on TV. But that's where this road leads.

In my glummer moments, I think about James as a boy who fell off a train and is running to get back on. Time and again he reaches it — but the train, too, is accelerating. Will the running never end?

We used a more upbeat image to tell James where he is now: he had rounded third and was getting ready to slide home.

Still, James raged and cried and insisted that he didn't have autism, that other children he knew did.

But he also had a lot of good questions. He knows that Larry gets tutoring in reading. Why doesn't that mean that he has autism? James and I had looked at an article about a kindergartner with cerebral palsy. Could that boy get better? Which was worse?

And he kept on thinking. Earlier this month, at the end of a day spent on a research study, he was offered a T-shirt with a picture of a brain. He angrily refused it. "I don't want to wear that to school," he said. "Nobody else in my class has autism."

In the car, he wept, asking "Why doesn't anybody else have autism?" The next night, during a sleepover, he told Larry about the incident — about how his brain was different, about how he used to have big problems. What did Larry say? I asked James. "That the only thing I know about is peanut butter!" he said, and laughed.

He had taken a chance and learned a lesson: Larry cares about him, not his label.

It made me realize: from now on who James turns out to be is going to be shaped more by him than by the work being done for him. James will be his own intervention.