



**Nonverbal and  
Low-communicating  
Autism:**

**the Forgotten Half  
of the Spectrum**

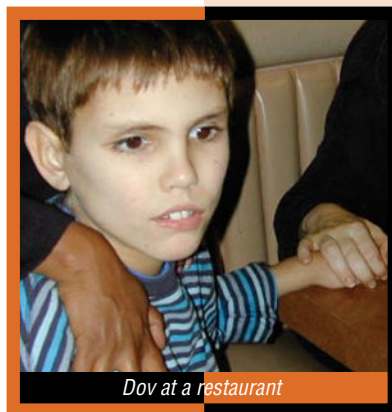
*By Portia Iversen*

**A miracle cannot prove what is impossible;  
it is useful only to confirm what is possible.**

- Maimonides, "Guide for the Perplexed"

**W**hen my son Dov was 21 months old he was diagnosed with autism. That was 15 years ago, and I had never heard of autism except to vaguely recall having seen a magazine cover of a child rocking in a corner whom they said was so emotionally traumatized and withdrawn that he had become "autistic." Now everyone knows about autism, and most people actually know someone who has the diagnosis. This is probably because autism occurs in one in a hundred children today. Back when Dov was diagnosed, they said autism was a rare disorder occurring in 2 - 4 children per 10,000. Today we know that autism is not caused by emotional trauma or bad parenting as was believed for 50 years after autism was first identified in the early 1940s. We know that it is a biological disorder that is likely to have many different causes.

By the time Dov was three, it was starting to look like he might be severely autistic. If he didn't talk by now, the speech therapist said, it was unlikely that he ever would. And not being able to talk was considered evidence of severe mental retardation. It still is, even today. No one thought Dov was going to get better, and that was unacceptable. We were running out of options, and we were running out of steam. We realized we had to pick our battles. One could spend all day, every day, fighting the insurance companies, the school district and the regional center to provide interventions they did not want to pay for. All these things had to be done, but where would the answers for Dov come from? What would be most likely to change his life for the better? The world might be giving up on Dov, but we would not. And so my husband Jon Shestack and I decided to start a foundation - we called it Cure Autism Now, and it would fund autism research. We wanted treatment and a cure for Dov and all those who suffered from autism.



Dov at a restaurant

### Turning to Advocacy

The power of advocacy is many fold - first, it can stem the tide of helplessness that descends upon anyone who is faced with a devastating illness or disability, and, second, it reminds the powers that be - the scientists, the government, the politicians and big pharma, what exactly is at stake - precious human life, and the quality of that life as it is lived, by both those who are effected and their families.

I can think of nothing more devastating than discovering that your child has a serious developmental disorder, except the news that there is no research going on into the disorder that has robbed your child of his future. That is the situation my husband Jon and I found ourselves in after our son Dov was diagnosed. Despair gave way to disbelief as we learned that the NIH was only allocating about 5 million dollars a year to autism research. Within a year, we had decided to start a research foundation. Here is an excerpt from my book *Strange Son* about the day we decided to start the Cure Autism Now foundation:

*There was nothing unusual about the night that it happened. Jon was trying to read the newspaper for as long as he could keep his eyes open and I was sitting at the end of the bed folding laundry. We didn't talk much at night anymore because we both knew that autism was the only thing on our minds and we didn't want to talk about it before going to sleep.*

*"We have to start a research foundation," Jon announced, looking up from his paper to see my reaction. "I've been thinking about it for a while," he said. "It's what we have to do if we want to help Dov."*

*This kind of thinking was typical of Jon; he always came up with ideas that most people would consider totally out of reach. This was something I loved about him.*

*"We have to get the government to give money to autism research," he continued, as if I knew what that meant. Of course the government gave money to diseases, I thought. Of course they were working on autism - weren't they? They had to be. Jon had been getting up at 5:00 a.m. lately to talk to people in Washington at the National Institutes of Health. There were no good figures on how much was being spent by the government on autism research, and the only way he could come up with an estimate was to get the lowliest accountants on the phone and go through each institute's budget line by line. There were four institutes that were supposed to be funding autism research, and he had added up their figures. Autism was getting around \$5 million a year for research, he told me. "Let me put it into perspective for you," he continued. "Alzheimer's - sixty million a year. Breast Cancer - six hundred million. AIDS - nine hundred million."*

*"But they must be working on autism," I said, shocked.*

*"There is no they," he said, carefully enunciating each word with an equal measure of wrath.*

*We sat there for what seemed like a very long time as this information fully took root in my mind. I had never seen Jon like this before. He was fervent, like some age-old rabbinical fire had been ignited in his soul. I could feel fate descending upon us. It was in the air, palpable and alive.*

*"Get on with your lives," the doctors had told us - and now at last we could. Because now we knew what to do. The year was 1995; we were starting the Cure Autism Now (CAN) foundation, and we would devote ourselves to finding treatment and a cure for autism from this moment on.*

## Worst Case Scenario

Learning that your child has autism is devastating, but no one talks about the second wave of despair that occurs for about half the parents of children with autism when they are told their child falls into the more severe or low functioning half of the spectrum.

When Dov was two years old, I used to sing and talk to him in the car while driving all over town to his therapies. I told him stories and jokes, riddles and their answers, facts and fiction, anything I could think of. I didn't know if he could understand a word I was saying, but there was always a chance he could – wasn't there?

"He may not understand you," his speech therapist said one day, suggesting that I not bother to sing or talk to him on these long car rides anymore.

"I haven't seen too many cases this severe," another therapist remarked, causing my hands to go cold and my body to feel shaky. Then one day, after an hour of spinning Dov on a swing while handing him plastic rings, the occupational therapist said that there was nothing more she could do for him. He simply was not responding to therapy, and there was no reason for him to continue, she told me at the end of his session. "Look," she said defensively, her big eyes staring at me uncomfortably from beneath her wavy black bangs, "I've been doing this for a year with him and there's no progress. There are a lot of other kids on the waiting list." To me there is nothing much sadder than giving up on a three-year-old. If Dov wasn't making progress, it wasn't his fault. He was only three and he had autism. It was her job to help him get better, wasn't it?

Apparently not – it seemed the world had given up on the more severe end of the spectrum. More accurately, they have never dared to hope for them.

## A Miracle at Age Nine - Dov starts to Communicate for the First Time

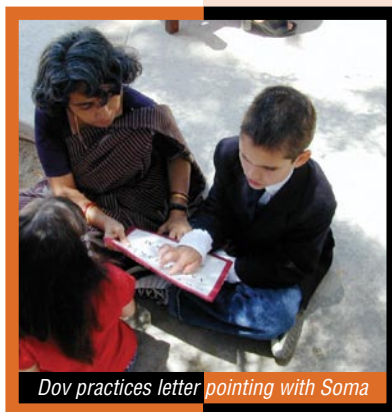
We never stopped trying. New therapies and schools, new vitamins and dietary interventions, new medicines and new people. And Dov grew and became a sweet young child with a loveable personality, as far as we could tell anything about him – for he still couldn't communicate at all. He couldn't point, write, gesture, sign or even nod his head yes or no. We tried Floor Time therapy, Applied Behavior Analysis, the Picture Exchange System, augmentative communication devices, speech and occupational therapy, sensory integration and every intervention there was. But Dov could not tell us anything, his wants or needs, his thoughts or desires.

All that changed suddenly when Dov was nine years old. I heard about a woman in India who had a nonverbal son with autism whom she had taught to communicate by pointing at letters on an alphabet board. Tito had not only learned to read and write, but he had a high IQ, and yet his behavior was low functioning like Dov's. This was the first time I had ever heard of a severely autistic, nonverbal individual who was able to demonstrate cognitive ability. Tito was twelve at the time and he lived in India with his mother Soma. He had written and published a book entitled *The Mind*

*Tree* when he was eleven, and the BBC had produced a documentary about him. I quickly tracked down Tito's book and read it and I watched the film about him, and thus began my determined search to find Tito and his mother. It took almost a year, but at last I tracked them down in Bangalore, India. I begged the Cure Autism Now foundation for a stipend to bring them to the U.S. I needed to know – the world needed to know – was Tito really autistic and if so, was he just a one in a million anomaly – or not?

Tito and Soma did come to the United States, and it turned out Tito was indeed autistic, and, when Soma started working with other nonverbal autistic children and succeeding in getting them to point and start communicating, it became clear that Tito was not one in a million. My son Dov was the first child Soma ever worked with after Tito, and even she did not know if her method would work with a child other than Tito. Soma went on to work with the nine children in Dov's class, and all of them began to communicate more than ever before. Here is an excerpt from my book *Strange Son* describing the first time I experienced Dov communicating.

*As we drove toward Soma's, I couldn't stop the flood of disappointing possibilities that was racing through my mind. Probably Soma would be holding Dov's hand or at least his elbow. Maybe she would be moving the alphabet board around under his hand. It's not that I doubted Soma, but there were a thousand ways to do this wrong, a million ways to confer unintended influence. I was prepared for disappointment, but I packed along the video camera anyway – just in case.*



*Soma opened the door and greeted us with her usual cheerful smile and brisk movements. The apartment looked pretty much the same as it did the day they moved in, except that the silk floral arrangement that had been on the dining table and every other nonessential item had been crammed into the closet, out of Tito's reach. Tito was stalking around the apartment, looking bored and agitated. I wondered if he was jealous – his mother had never worked with anyone else before.*

*Wasting no time, Soma marshaled Dov over to the couch. A spiral notebook and a few colored markers were on the coffee table, along with a textbook and a piece of cardboard with the alphabet printed in lowercase letters, the same kind Soma often used with Tito. Dov sat cross-legged on the couch next to Soma, looking toward the window where vertical blinds split the sunlight into irresistible stripes of light. Yet he did sit down next to her and he was staying there, I noted to myself, trying to be positive.*

*Soma opened the textbook and began to read out loud at an incredibly rapid pace: "A galaxy is a group of stars. . . ." Why was she reading to him about the solar system? How could she expect Dov to understand her when she was reading so fast, not to mention in that heavy Indian accent? I popped a tape into the video camera and turned it on anyway.*

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Gabriel stuck his face into the lens, crossing his eyes, hoping to get some attention. “Stop it!” I hissed under my breath, not wanting to disturb Soma as she worked with Dov, even though he seemed to be paying no attention to her as he continued to stare in the direction of the blinds.

Soma stopped reading and without pausing a millisecond she demanded: “Okay! A galaxy is? ... C’mon, show it!” Dov turned toward the board Soma suspended in midair in front of him. I held my breath. “C’mon! Show, show, show!” she commanded, prodding his knee with her thumb as she urged him on.

Then, in a moment that remains more clear in my mind and more astonishing than any man walking on the moon, Dov raised his hand – by himself – glanced tentatively at the board, and pointed to the letter G. Was it chance? I didn’t have time to wonder as Soma forced ahead.

“Okay, ‘G,’” she said, simultaneously writing it down. “Good, good! You can do it! C’mon, show it!” Again, Dov glanced at the board, looked away, and pointed, this time to the letter R. “Go, go, go!” Soma kept up the animated urging.

G-R? What was G-R? It didn’t make sense. I looked through the camera lens to be sure I was getting everything anyway. I saw that Gabriel had crawled up behind them on the couch. “Gabe! Get out of there!” I whispered fiercely. Ignoring me, he moseyed in closer to them. “C’mon!” Soma continued.

One by one, Dov pointed out the letters as Soma wrote each letter down and urged him on. “‘G-R-O-U-P!’” she spelled out triumphantly. “Yes, we are getting it! Very good!! C’mon, show!” she continued, never letting up. Finally there were three words: “Group of stars.”

Group of stars? Of course—a galaxy is a group of stars! Had Dov actually answered that question? Was it possible? It seemed true. How could a boy who could not spell his own name be spelling out an answer like that? Soma read it again, “‘Group of stars!’ You are right! Keep going!”

For the next half hour, I watched in awe and fascination as Soma read other science facts to Dov and questioned him about what she’d read. It seemed crazy, absurd. Dov didn’t know his colors. He didn’t know the alphabet or numbers. We’d been trying to teach him these things since he was three years old and he had made almost no progress at all. It didn’t make sense.

Yet again and again Dov pointed at a letter, then another, sometimes missing one, sometimes hesitating, but always continuing until he answered Soma’s questions. Dov seemed to be demonstrating a level of intelligence that I had never suspected or dreamed he might possess.

I watched Soma closely. What was she doing?

She was talking nonstop, in an intense, loud voice; she wasn’t holding his hand, she wasn’t even touching his shoulder. She was prodding his knee with her thumb. Beyond that, I could detect no other clues as to how she was so miraculously getting Dov to point and to answer questions I didn’t even know he was capable of understanding.

I could barely begin to comprehend what this meant. It meant that Dov was intelligent – far more intelligent than we’d dared to hope or than he’d ever been able to show us. It meant that he was not retarded. It meant that he’d been in there . . . all these years. I could barely keep from crying.

The world can be changed forever in a day. Yesterday, my world as I knew it was destroyed. And on this day, an entirely new world was born.

Everything I thought I knew about Dov, about learning and intelligence, about language and speech, about development and behavior, about thinking and being, was turned upside down.

Once I had met Tito and Soma and especially after my son Dov began to communicate after working with Soma for a relatively short time, I felt a huge responsibility to get the news out to the world. I now carried within myself the enormously important knowledge that some, if not many, low functioning people might have far better cognitive ability than we suspected and that there was a way to help them learn to communicate. I tried to think of the best way I could to get the message out, and in 2007, I published my book *Strange Son*, describing my experience with Soma and Tito and the tremendous breakthrough they had made possible for my son.



### New Focus of Advocacy – the Nonverbal and Low-communicating

The question must be asked: How many others are there like Tito and Dov? Soma and Tito eventually moved to the United States and in the eight years since Dov first began to communicate, Soma has worked with hundreds of students of all ages and many levels of functioning, although most would be described as low functioning. The vast majority have shown higher cognitive ability than previously detected, and all have improved their ability to communicate and, thereby, their quality of life. Many have even turned out to have high intelligence like Tito, intelligence that, without access to a means of communication, no one would ever know about.

Today, intensive early intervention is the recommended course of treatment for autism, and yet there is a significant group of “non-responders.” These are the children who are not talking by age three and for whom most therapies do not result in any improvement. The assumption is that these non-responders are the hardest hit by the disorder and that they are basically untreatable.

Autism is described as a spectrum disorder ranging from mild to severe, with the nonverbal falling in the most severe end of

the spectrum. These individuals are usually referred to as low functioning and by default labeled mentally retarded. When therapies fail these children, their education comes to an end, and they are relegated to what has struck me as a nursing-home-like environment. Based on the assumption that if you cannot speak you are mentally retarded, these people are relegated to a lifetime of being warehoused, their greatest possible aspiration – to be treated kindly. And yet we do not even know if they can understand us, and we know nothing about their cognitive abilities or emotional characteristics.

The truth is we know nothing at all about the low functioning end of the spectrum. Because they can't communicate, it is assumed they also can't understand – no expressive language is equated with no receptive language. That we don't know the most basic things about this subgroup is made even more amazing by the fact that it is estimated to make up about half of the autism spectrum. There are no actual numbers because there has never been a scientifically validated diagnostic description for the low functioning – the nonverbal and low-communicating (those who can speak but cannot communicate). Without such a scientific diagnostic description, these individuals cannot be counted or reliably included in research studies.

Thus, the most basic questions remain unanswered – we don't know if they have receptive language because we don't know how to test them. There are currently no studies specifically focused on this group, and they are almost completely excluded from autism research in general. In spite of the critical need for communication interventions for these nonverbal and low-communicating individuals, there are no such studies underway yet.

Some progress is just beginning to get underway to change all this. In 2007, Cure Autism Now merged with the new organization Autism Speaks. And, in 2008, I initiated a project to focus on nonverbal autism called: "Characterizing Cognition in Nonverbal Individuals with ASD" (CCNIA). So far, this group has held three major workshops to determine how to develop a research diagnosis for this group so they can be counted, included in research and start to have research focused specifically on them. There is much promise in technologies that can potentially test the cognitive activity and especially whether receptive language is intact, in nonverbal, non-compliant individuals. The good news is this type of technology has already been invented for use with locked-in syndrome patients (who cannot actively participate in any behavior dependent activity) and Autism Speaks is now planning to fund a proof of principle study of this very technology in the nonverbal population.

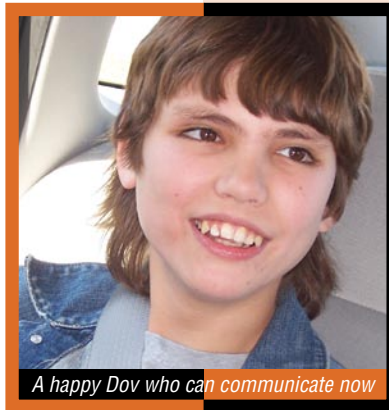
In fall 2008, I was appointed to the National Institute of Mental Health (NIMH) Advisory Council, and, in that role, one of the things I am prioritizing is the nonverbal and low-communicating segment of the autism population and bringing attention to the disparity in their inclusion in federally funded research. If you stop to think about it, every study that does not include them is only really getting half the results they are claiming – because half the

ASD population is not being included! Disparity in inclusion of women and ethnic and racial minorities has been a major problem until new policies were instituted that require their inclusion in federally funded research.

In another incremental movement forward, NIMH and the National Institute on Deafness and Communication Disorders (NIDCD) are in the planning stages of a meeting (the first ever!), focused on nonverbal autism. It is my hope that with pressure from the public (this means YOU!) that the NIMH will step up to the plate and follow this initial workshop with some funding dedicated to jump starting this research. You can submit your views through the Interagency Autism Coordinating Committee which accepts public input once a year (usually in August), see: <http://grants.nih.gov/grants/guide/notice-files/NOT-MH-09-013.html> Also see: <http://www.iacc.hhs.gov/> to view recent public input – many of us who are advocates for the so-called low-functioning officially submitted our input, urging the NIMH to include and focus on the nonverbal and low-communicating population with autism in their research efforts.

If you have a nonverbal or low-communicating child, you are probably wondering how to get more information about this communication method. After my book came out, many families and therapists contacted me with this request and so I wrote a manual on how to get a child started pointing and communicating. I also started a community website where you can share your experience in a discussion forum focused on these issues and the obstacles and triumphs that this community has experienced. You can also share videos that show how nonverbal kids have progressed toward learning to communicate. There is no better way to learn than from others who are already on the journey on which you are just starting out. You can join the community website at: [www.strangeson.com](http://www.strangeson.com) where you can also find the downloadable manual available for free.

I wish you all the best in your hopes and dreams for your special person whether it be your child, your sister, brother or student. I commend you from the heart, for having hope when the world tells you to give up on that person. And I encourage you to keep trying, never give up, and prepare yourself for "unknown miracles that are already on their way." ◀



A happy Dov who can communicate now



Portia lives in Los Angeles with her husband Jon Shestack and their three children. She is author of the book *Strange Son* (Riverhead, 2007). Portia currently serves on the NIMH Advisory Council and is also the founder and director of the Descartes Institute, a nonprofit organization established in 2003, whose mission is to improve communication, education and the quality of life for nonverbal and low-communicating individuals. For more information see: [www.strangeson.com](http://www.strangeson.com) and [www.portia@portiaiversen.com](mailto:portia@portiaiversen.com)