

Jacob's Story: A Miracle of the Heart

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Editor's note: In order to protect his son, the author of the following article has chosen to remain anonymous. However, he is eager to respond to parents who are facing similar challenges. You may communicate with "Jacob's father" by writing to him c/o Emily Fenichel, **ZERO TO THREE**, 734 15th Street, N.W., Suite 1000, Washington, DC 20005-1013 or by sending an e-mail to e.fenichel@zerotothree.org.

My wife and I are both social workers. We have three children. Our youngest Jacob, is a tall handsome boy with sandy brown hair and his mother's eyes. This is his story. Or at least, his story to date. Jacob Reuben was born on March 20, 1991. Jacob was my grandfather's name. Reuben is Hebrew for "look, a boy", which is just how we felt when Jacob was born. We were convinced that we were set. We had surpassed our quota of 2.6 children and were ready to engage parental auto-pilot. I had just begun a prestigious job and was working 10-11 hours a day. The children would be fine. We hired a nanny to watch Jacob during the day.

As each of Jacob's early milestones passed we felt that we had taken another step toward our goal of having three normal children. We were on our way to the perfect American family. Yet, somewhere back in our minds we had some doubts. Jacob seemed different than the girls. He had some unusual attributes. There were times when we would be holding him and he would arch his back and scream so loud that it was painful for us. Weaning him was extraordinarily difficult. There seemed to be almost no non-verbal give-and-take when we read him a book. He refused to wear gloves, hats or boots. He didn't seem to mind or notice when he banged his head or stepped on a sharp object. Two or three times a week he would pull all the books from his shelves. Twice he pulled his dresser down on himself. At two years he was still not speaking. He had said one or two words, but his language development had not only ceased but seemed to have reversed - he was speaking fewer words rather than more. At first we rationalized his differences. He was a boy; boys are different. He'll speak when he is ready. He's just different than other kids. We had a foreign-born child care provider; maybe she wasn't communicating with him adequately.

At his one and a half and two-year check ups we shared our concerns with the pediatrician. He assured us that it was too early to be worried.

Jacob continued not to speak and his behavior became increasingly strange. He would run in circles and shake his head from side to side. He didn't seem to know what to do with his toys. His only play was dropping rocks. On several occasions, he smeared his feces over the walls. Of all the strange, unexplainable symptoms we were most alarmed by his increasing isolation. More and more he was unresponsive. He no longer seemed to notice when another person was in the room. He would wander off in public settings, seemingly not caring that he might get lost or separated from us. He would watch videos for hours, totally entranced. We could stand behind him and yell - he seemed not to notice. We thought he might be deaf.

In spite of the pediatrician's assurances, both Rebecca and I knew that something was very wrong. Finally, when Jake was two and a half years old, we had him evaluated. We wanted the best and took him to a child development center at a major teaching hospital. We were placed in a large, more or less empty room, and over the course of the day, a series of experts paraded in and out to administer their tests.

We remained in that room all day as the procession of "specialists" went on. The psychologist asked Jacob to build with blocks as I held him tight on my lap. He refused to sit still so I was told to restrain him by crossing my arms and legs around his body. Occupational therapists told him to walk up and down stairs and across balance beams. An audiologist put him in a dark soundproof

room to check his hearing. A development pediatrician poked him and bent his legs to assess his muscle tone. Jacob spent most of the day running in circles.

I knew that Jacob has serious problems but I also felt that these professionals were seeing him at his worst. In this alien environment, a succession of strangers appeared and disappeared. It was disorienting to me -- I can't imagine what it was like for him.

In spite of all his strange behaviors, both Rebecca and I sensed that Jacob was extremely bright. We both knew that he had a special connection to us and his sisters. I showed the psychologist a picture of Jacob, with a gleeful expression, chasing his sisters with a water hose -- in my mind, the picture indicated that there were times when he was clearly engaged and connected. I told her of our sword fights, one time when he and I seem to be connected. She dismissed my impressions with a patronizing glance. The evaluation team members seem to have little interest in our perceptions of Jacob's capabilities. After all, they were the "experts"; we were only his parents.

Our evaluation at this major medical center left us with a diagnosis we didn't understand and a deep sense of despair. Pervasive Development Disorder. A phrase that did not mean anything to us. There was no clear description of this ailment or of its causes. We were told that there was no way of guaranteeing Jacob's intelligence and that he might be retarded. There was no discussion of a treatment plan, other than the psychologist's comments that we should consider residential placement and contact our local school system.

When your child has a fever you give him Tylenol. If she breaks a finger, you go to a hospital and they take an x-ray. But if you are an average parent, and assume you will have average kids, where do you go, what do you do for pervasive development disorder? We were given one lead. Contact the Autism Society.

The next weeks were among the most painful I have ever experienced, as we began to prepare ourselves for a lifetime with a disabled child. I would lie away at night, unable to sleep. I had no appetite. I could think of nothing but the son that would be lost to me forever.

It was a stroke of luck that brought us to Dr. Stanley Greenspan. Rebecca's brother had a friend who was an occupational therapist in New York. She recommended we speak to Greenspan. We almost didn't go. After all, Jake had been evaluated at a major teaching hospital and had been seen by at least 10 experts, each of whose coat was whiter than the next. It wasn't until an acquaintance gave us a copy of the *Zero To Three* bulletin on reconsidering the diagnosis and treatment of very young children with autistic spectrum or pervasive developmental disorder (October/November, 1992) that we decided to call.

On Saturday, November 27, 1993 at 11:00 a.m. we drove up the long gravel driveway to Dr. Greenspan's large white shingled house in Bethesda, Maryland. And on that day we were given our son back. Dr. Greenspan listened to us in a way that validated our experience and our thoughts. He spent time learning about us and about Jacob and asked questions that forced us to focus on details. Pulling out the ubiquitous video camera he told us to play. We both took turns trying our best to play with Jacob. Then, with the words, "Now I'm going to teach you play with your son," Jacob's healing began. Dr. Greenspan told us about his conceptualization of multisystem developmental disorder. He talked about sensory integration, and explained what processing meant. He taught us about floor time and demonstrated how we were to build a connection to Jacob one circle at a time.¹

At the end of the session, Jacob refused to leave Dr. Greenspan's office. He lay on the floor screaming. He had found a place where he could be heard.

We returned the following week and the treatment plan was laid out for us. It was overwhelming. It was life-altering. I had no idea how we could carry it out or, for that matter, pay for it. Two to three sessions of speech therapy a week. Two sessions of occupational therapy. One session of play therapy. An educational consultant. A complete change in his diet. No sugar, no chemicals, no salicylates. I had never heard of salicylates. I still don't know what they are.

And floor time. Four hours a day of floor time. Four hours a day for two parents, both of whom worked full time, with three children.

Hope was the most important thing Dr. Greenspan gave us. But he also gave us a plan, a call to action. He explained to us what the underlying issues were and how we were going to address them. He empowered us with understanding and then he put us to work. He made Jacob's treatment our responsibility, not only as the shleppers to sessions, but as key players. The responsibility for floor time, for making circles, for building the connection was ours.

We altered our lives. We took Jacob to his therapies. We stopped watching TV. I gave up all sports. We stopped going out. We changed our diet. Rebecca began shopping at four different stores for food: the supermarket, two different health food stores and the kosher butcher. We blew bubbles, used sign boards, and put pictures of family members, therapists and foods on our walls. We used brushes, lotions, vibrators and massagers. We sprinkled vitamins in his food and bought cases of pear juice. We bought organic fruits and vegetables and sugarless lollipops. We learned sign language. We sat through three cycles of Tomatas auditory training. We went to a nutritionist and a homeopathic physician. We drilled into our ceiling and put up a therapeutic swing and nailed a 4 foot by 4 foot mirror into our den wall. Each therapist gave us a list of daily actions we were to take. We couldn't keep track of everything so we made lists and charts. Massage cheeks twice a day. Blow bubbles once a day. Vibrator twice a day. Massage palate once a day. Lotion once a day.

Most of all we played, or in our family parlance, we "made circles." In the beginning 4-5 hours a day, more on weekends. Jacob would wake up between 4 - 5 am, and either Rebecca or I would drag ourselves out of bed for 2 hours of pre-work play. We would then leave our jobs as close to 5:00 p.m. as possible and play for 2 more hours in the evening. We had a wonderful au-pair who was fully engaged, and our daughters were also involved. We took weekly trips to Toys-R-Us and Toy Traders. Our den filled up with cars, trucks, street scenes, fire trucks, boats, planes, construction equipment, tanks, helicopters, ninja turtles and power rangers. We have every animal imaginable and most dinosaurs. We have more swords than the knights of the round table. We have more Legos than Denmark. We stopped seeing friends. We were too busy making circles. Our time with Jacob became sacrosanct.

Beyond the floor time, we used every setting to make "circles." The context, the setting, the issues were less important than the opportunity they presented to engage in interactive circles. We made Jake work for everything. Before we had begun treatment we had become proficient at anticipating his needs. After all, Jacob's capability to communicate was severely limited. Once the treatment began we trained ourselves to force him to "ask" in whatever way he could for whatever he wanted. He would scream in protest, and we would use the opportunity to make some more circles.

The classic description of autism includes children who are emotionally isolated, alone, and disconnected. And, in fact, before we began his treatment, Jacob had become increasingly isolated. I'm not a psychologist, but I believe that he just stopped trying. It was too hard, perhaps too scary. He couldn't figure out what was expected of him. The world had become too confusing, and so he withdrew from it. He would seek out the comfort of quiet, dark places and sit by himself. He would lose himself in the bright colorful images of cartoons and animated movies. Under the guidance of Drs. Greenspan and Wieder we rebuilt Jacob's connection to us and to the

world -- but on his terms. We were drilled to always follow his lead, to always build on his initiative. In a sense, we could only ask Jacob to join our world if we were willing to enter his.

In the beginning our "circles" were basic. He would drop rocks and we would catch them. He would want to put pennies in a bank and we would block the slot. He would want to run in circle and we would get in his way. I remember a cold fall day when I was putting lime on our lawn. He dipped his hand in the powder and let it slip through his fingers. He loved the way it felt. I took the lawn spreader and ran to the other part of our yard. He ran after me. I let him have one dip and ran across the yard again. He dipped, I ran, he dipped, I ran. We did this until I could no longer move my arms.

Other than Drs. Greenspan, Wieder, our other therapists, Rebecca and me, I don't think anybody really believed Jake would get better. The entire rest of the world was operating on a different set of assumptions regarding who he was and what he could accomplish. Our friends and family, for the most part felt sorry for us. There was certainly no real awareness of what all our effort was about. Our most difficult and frustrating encounters were with the school system. We chose not to send Jacob to public programs for children with disabilities. Early on in our discussions with special education officials, it became clear to us that we were not simply talking about different methods or different settings -- whether Jacob would attend a special program or would be mainstreamed (see Kalmanson, this issue).

Our differences were not about programs but about paradigms. The disagreement was not about what Jacob was entitled to but what he was ultimately capable of. After a year in which Jacob made great progress in a mainstream program with supportive services, we were told by public school officials that we had done a wonderful job, and now Jacob was ready for a special needs program. We were operating on different assumptions of what Jacob could accomplish. We believed that after two to three years of intensive intervention, Jacob would be fine. They assumed that he would always have special needs. We were talking a different language. Jake was listed as "multiple handicapped" on Board of Education documents. Rebecca and I never accepted that label, nor will we ever accept any like it.

While all of this was happening, Drs. Greenspan and Wieder were pushing us forward and daring us to dream. I will quote Dr. Greenspan verbatim: "You should not place a ceiling on Jacob's capabilities. He might not go to MIT, but he just might." Yes, we had to work hard for this dream. This floor time thing is difficult. - Its hard work. Its not always easy to figure out. Both my wife and I are social workers with training and experience working with children and adolescents. But it seemed to us that every time we had figured out the key to floor time we were instructed that we were being either too directive or not directive enough. Our sessions with Dr. Greenspan followed a pattern. He would ask us to demonstrate our floor time techniques, and then he would critique our methods. We would leave, Rebecca would cry, and I would be angry at myself for not getting it right and therefore delaying my son's progress. We would go home and push harder.

Jake's progress was rapid and remarkable. After less than two weeks he was more connected and his non-verbal communication began to strengthen. We began to take weekly trips to the museum. He would hold my hand as we walked through the exhibit. Within one month he began to engage in symbolic play. His non verbal communication developed rapidly. Speech came more slowly, and Jacob did not say a word for the first nine months of therapy. Only once he began to get better did we realize how serious his condition had been. When he began treatment, he could not organize is body to point his finger. It took three months of speech therapy for him to begin to do the hand movements to the "Wheels on the Bus".

Jacob's first word, spoken in July of 1994, was "meow," followed shortly after by, as you might expect, "cat." By the end of the summer, he had most of the animals down. By the fall he had moved on to dinosaurs. By the following summer he was speaking in full sentences. Today he speaks for days at a time. He talks from the moment he wakes up to the moment he falls asleep,

as if he is making up for lost time. He wants to know everything. "How does a live chicken become an eating chicken? Why are microbes so small? Why do policemen wear badges? Why are dinosaurs extinct? What is French? (A question I often ask myself). Why do ghosts glow in the dark?" He is not satisfied with answers that do not ring true or that do not satisfy his standards of clarity. He will keep on asking until he gets it. Rebecca and I have become expert definition providers. Just last week, we were faced with the ultimate challenge: "Dad", he asked: "Is God real or not?" And then, just to make it a bit more challenging, he added: "How do miracles happen?"

Jacob offers Rebecca and me items from his great storehouse of knowledge --the reason why the planet Mercury is hot, the uses of electricity, the dangers of poison. A quote from a recent dinner conversation: "Bats are extraordinary because they eat mosquitoes and moths too but not butterflies because they are beautiful." When he is not talking he is singing --Zippity do da; She'll be comin' round the mountain; This old man; Shalom Aleichem. (He sings in two languages.)

Jacob is a joyous child with a great sense of humor. Several weeks ago he spied a bug on the floor of the den, grabbed a shoe and proclaimed, "I have a shoe and I'm not afraid to use it!" Recently, he dropped a coin on the floor and yelled out: "Runaway penny!"

Jake and I play every day. We begin by choosing a theme: cowboys, knights, space, scuba, pirates or soldiers. Then, together, we build a story -- he has a wonderful imagination. Remembering Dr. Greenspan's admonition, I let Jacob be the director. Sometimes the stories are what you'd expect of a five year old boy --good guys and bad guys, gun fights, sword fights and karate fights. Other times, we create epics. In a recent episode the snake helps the gold miner to build a gold mine. The gold miners try to use their pick axes to remove the gold, but its covered by rocks so they have to use dynamite. They strike gold, take their money into town, and buy guns, knives and lanterns to prepare for the bandits. The bandit comes, there is a big fight, and the gold miner captures the bandit, puts handcuffs on him and takes him to jail. Often, the play provides glimpses of Jacob's inner world. Among the recurring characters in his stories are Sheriff Ned Bardy and his sons, Chris and Alvin. Sheriff Ned Bardy is from a book we read and Chris I can't answer for, but Alvin was my father's name. We have spoken of him often, and Jake struggled for days to understand why my father had died and what being dead meant.

Jake still does some things that one might consider odd. When he gets excited, often in play or while watching a movie, he shakes his head and runs back and forth. He hums a lot. He can spend 5-10 minutes jumping on his trampoline. You might say he has a difficult time modulating his emotions. On the other hand, you might say that is has a wonderful capacity for pure, visceral joy -- a quality many people in our society could benefit from.

In general, I believe that the same issues that made it so difficult for Jacob to learn and to connect with others provide him with special gifts. I believe that Jacob, quite literally, experiences and, consequently, organizes the world in a way that is quite different than you or I do. The challenge is not to enable him to see and to approach the world as we do. The challenge is to enable him to make sense of the world in a manner that make sense for him. The goal is not to make him normal. The goal is to unleash his special gifts. That is the challenge for all of us. Not simply taking damaged children and making them whole but connecting with their special gifts, enabling them to succeed in their special ways. Our goal is not to enable them to find their way in our world but to find the appropriate ways for our worlds to meet.

I ask that you consider the following in your work with children and their parents:

Help parents, be sensitive to our needs, but remember who the client is. Don't let us off the hook. Push us, challenge us. Keep us on task. We must be a main protagonist if our child is going to get better.

In many communities, the structures and services have not caught up with current innovations and new approaches to intervention. Empower us to be advocates on behalf of our children and embolden us to be subversive when we need to be.

Knowledge and understanding will empower us. Confusion and lack of clarity are disabling. Take the time to explain the issues to us with words we will understand.

Finally, incremental changes in practice and perceptions will not suffice. Rather, a radical paradigm shift concerning the fundamental assumptions regarding who these children with severe disorders in relating and communicating are and what they can accomplish is called for.

Rebecca and I get one or two calls every months from parents who have children with developmental or learning issues. They find our number from our friends or family members who, upon hearing of their pain, frustration and fear, tell them about us. They call from New York, from Florida, from Pennsylvania, from Minnesota. We tell these parents about Dr. Greenspan, about sensory integration, and about floor time. Most of all we tell them about Jacob. Sometimes we are able to connect them with members of Jacob's treatment team. Sometimes we never hear from them again.

In another city, there is a child just like Jacob, with all his intelligence, all his gifts and potential. The child's parents will never hear of Drs. Greenspan, Wieder or Shanok. They will not know of floor time, sensory integration or Tomatas. They will not have access to speech therapy or occupational therapy. Their school system will have limited services for them. Their pediatrician will misdiagnose their child's symptoms. The child will be relegated to programs for the multi-handicapped, to institutional settings. We must find these families and assist them.

For every parent who calls us and for every child seen by professionals reading these words, there are thousands more who will not benefit from the astonishing work that is being done with very young children who have severe difficulties in relating and communicating. For every therapist or assessor who has opened his or her mind to new approaches and new paradigms, there are hundreds more who will ask a parent to restrain his child as they attempt to administer standard psychological tests and then base their diagnosis on those tests alone. For every school administrator who is open to innovative approaches and who respects parents' choices, there are tens more who will limit a child's options in order to preserve the status quo or hold down costs. We have much work to do.

Jacob, now five and a half, is not quite finished with his therapies. There is work still to be done. But in three years Jacob has been transformed from a mute, isolated, frightened boy, who seemed to be destined to spend his life in institutional settings or special needs programs to a delightful, delicious, warm child who is learning at a mile a minute. He is the loving, warm child that every parent wishes fr. Four months ago, we took Jacob to be interviewed and tested for admission to kindergarten. We said nothing about his background, except that he was a late speaker. He passed both interview and test with flying colors. Next year, with the help of God, he will enter kindergarten, not as Jacob the child with pervasive development disorder, not as Jacob the autistic child, not as Jacob the multiple handicapped child, but as Jacob the tall handsome boy with sandy brown hair and his mother's eyes. Increasingly, Rebecca and I have permitted ourselves the great luxury of a creeping sense of normalcy.

Jacob's recovery and development are a miracle. It is a participatory miracle. It is more a miracle of the heart than it is a miracle of science. It is a triumph of the healing capacity of love. Jacob will go to school and he will have friends. He will join a soccer team and play an instrument. He will be bar-mitzvahed and will go out on dates. He will drive a car. He may not go to MIT, but he just might. But then again, that will be his choice.