

Jacob's Story Part Two:

Each Day is Another Adventure

This week, over three years since I presented Jacob's Story at ZERO TO THREE's National Training Institute and it subsequently appeared in the *Zero to Three* bulletin (April/May, 1997), I received two letters from parents who had read the story. One letter was from Manila, the other from South Carolina. Each letter told the parents' story of their autistic children. One parent spoke of having two autistic boys. In the three years since the publication of "Jacob's Story" we have received letters and e-mails* from around the world. Parents with children with serious developmental delays and communication disorders tell us of their stories and ask for guidance and direction. I am grateful for their kind words and pleased that Jacob's story has been helpful.

Rebecca and I have received numerous requests for a follow-up on Jacob's story. It is a difficult thing. Telling Jacob's Story, first before an audience and then in print, represented somewhat of a catharsis for us. Beginning with a difficult and painful challenge, we persevered and, with the help and guidance of gifted professionals, were able to claim victory. It was an intense, tumultuous period filled with remarkable developments.

The subsequent three years have brought us a lovely sense of normalcy. We begin our days like most families with breakfast and car pools. There are homework, piano lessons, play dates and cub scouts. Pokemon has entered our lives with a vengeance. And while Jacob continues to make consistent progress, the last third of his nine years have been, well, pretty normal. His friends and his teachers do not know of his background. The school year is ending and he will continue on to third grade. We have begun to think about sleep-away camp.

Having begun this journey with an evaluation that labeled our son as having pervasive developmental disorder and being told that he would have to be institutionalized, we find that the normalcy of his and our lives is, perhaps the greatest miracle, the greatest victory of all.

I, therefore, begin Jacob's Story, Part 2 with a simple yet glorious statement, "Jacob is fine." As I write, he is practicing piano in our den. He is tall and handsome and strong. He has friends and plays Gameboy and computer games. It is his job to feed the dog and he does it twice a day without a hitch. He loves Calvin and Hobbes and shares Garfield's impish sense of humor. At our recent Passover Seder, he recited the four questions, the traditional role for the youngest child at the table.

Jacob is in his third year in his current school, almost at the end of second grade . . . So far so good. For the first two years we waited for the phone call from the teacher to tell us he is not right, not appropriate, not succeeding. But for three years he has come home with a smile, with work marked with "excellent," "well done," "terrific" and all the appropriate stamps. Our most recent parent-teacher conference was wonderful. The teacher had only praise for him. He is reading on grade level. His math skills are on grade level. His teacher tells us, "He is a delight to have in class."

This not to say that school is always a breeze. Rebecca or I work with him every night for at least an hour. His mind wanders. He sharpens his pencils, takes another break for apple juice. But, ultimately, although sometimes not until the next morning, he makes his way through it all. He signs his name in cursive on all of his assignments. He places them

* E-mail messages sent to e.fenichel@zero tothree.org will be forwarded to Jacob's father.

in his knapsack, makes his lunch, and gets ready for school. Perhaps the most wonderful breakthrough of the year is that he is reading! It has been a slow process but he is reading. For us it is another milestone, another signal that he will be okay. Now he is learning Hebrew. He struggles putting together the consonants on top and the vowels on bottom and to remember that the letters go from right to left.

While the academics of school seem to be going wonderfully for Jacob, his relationships with his peers still seem to be a challenge. He is not quite there yet. We organize as many play dates as we can and they seem to go fine. Friends will now stay over for 2-3 hours. Because his interests are different from those of his peers, not all his classmates want to get together. Our list of available play date partners seems limited to a small cadre of friends. We keep on calling.

Group situations are more difficult for Jacob. Generally, he finds himself on the periphery. Kids make fun of him. He doesn't participate in sports with them. They say he is

Little League baseball was also hard. He stood in the infield, complete with his bright red uniform. A slow grounder would head in his direction and he would just stand and watch it approach. I would cringe and wonder what the other parents were thinking. At one point Jacob turned to me and asked: "Can't I play a game that I can move around more?" We tried soccer, with little more success. He could not "stay in the game" and was unable to keep focused.

The implications of sports in our society go beyond the playing field. Especially for young boys it is often the entrance pass into the peer group. Will his failure in sports isolate him from his peers? I'm sure I am more sensitive to his difference than he. I want him to fit in, to be one of the boys. Perhaps, as I look back on my own childhood, I was never one of the boys. My early days and sleep-away camp experiences were awful. . . painful. I console myself with the thought that I survived. By the time I was in high school, I had grown into my body and had become a good athlete. I was one of the boys. Perhaps it is unrealistic for a parent to think that far in advance but I want everything to be just right—and I want it now.

Yet Jacob is different. There is something quite remarkable about him. His extraordinary imagination and curiosity are clearly on another level than his peers. Recently, after much urging from him (kvetching and whining—two elements of communications he seems to have mastered rather nicely), we bought him his own camera. The first roll of film was sacrificed when he opened the camera to see how it was doing. The second roll was completed in fine fashion. Yet, for Jacob, it was not enough just to own a camera. It was an opportunity to learn more. How does it work? What does the lens do? Why do you need negatives? How do you get the pictures to be bigger than the negatives? We make wonderful, rich interactive circles of communication. I draw him pictures displaying how an enlarger works. We leaf through Macaulay's *How Things Work*. Jacob cannot wait to see the outcome of his picture taking, so we leave the house early Monday morning and drop off the film before school. That evening, he reminds me three times to pick up the photos. He possesses an amazing memory—when it involves something he wants. The photos arrive the next day and he makes two albums—one of friends and one of family members. Now he wants an enlarger.

"Dad, don't they know that different kids are good at different things?"

different and it breaks my heart. Most of the time Jacob seems not to mind. He is happy with himself. He sees himself as being smarter than his peers. He thinks that they just don't get it. They don't understand him; they are not at his level. One day, he came home from camp and reported that the kids were making fun of him. My heart sank. But he followed, "Dad, don't they know that different kids are good at different things?"

Sports and athletics are difficult. We got him a new bike for his eighth birthday. A year later he has yet to learn to ride. After much urging we finally go out for the lesson. He dons his helmet. We walk down the driveway. He is off, down the street, tentatively, with my hand grasping the back of the bicycle seat. Time and again I repeat: "Keep pedaling," "Look forward," "Don't worry, I won't let go." Yet as soon as he picks up some speed he pushes the pedals backward to slow down. He is nervous, scared. The lessons never last more than 10 minutes. More often than not we both end up angry and frustrated.

He wants to know what kind of light you can use in a darkroom.

One evening, Jacob wants to know how cities began. I'm not an expert on how children learn, but, to my thinking, it is an extraordinarily complex question. It involves the awareness of cities as complex social and economical constructs. I answer him the best I

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can, beginning with a description of how long ago people would meet all their needs by themselves. I speak about how increasingly people began to rely on each other and individuals took on separate tasks and jobs. He seems to understand the concepts. Another day, Jacob postulates that there must be an opposite force to gravity. He states that on certain planets, like earth, gravity is the stronger force and so people don't float away. On other planets the other force may be stronger. The physics may not be exact—but that he is wondering about it and theorizing is astonishing.

Floor time still provides rich, wonderful opportunities for circles of communications. His imagination is lovely, rich and multi-layered. One morning's play brought both a delightful dialogue between us as well as a fairly high-level discourse on growing up vs. remaining a child. No props were involved, no toys, no action figures, just our shared imagination. Jacob became Super Kid—protector of children. I became Dr. Grownup spreading the evils of the bizarre world of adulthood. Dr. Grownup swoops down, takes away children's hot dogs, hamburgers and fries and replaces them with liver and brussel sprouts. Children are locked in their messy rooms and forced to place every toy on the appropriate shelf. A battle of epic proportion ensues. Each character brings forth his most mighty weapons—Super Kid uses powerful farts and burps while Dr. Grownup fights back with grownup morning breath. Intergenerational Armageddon continues until Super Kid handcuffs Dr. Grownup in a space ship and sends him off to burn up in the sun.

The story is too much fun and Super Kid demands more. We create henchmen for Dr. Grownup:

- Mr. Taxman who taxes all the kids' lemonade money, taxes the toys and then takes the dog's bone and taxes that.
- Nameless Bureaucrat demands that children fill out multiple forms for everything. Super kid sends Nameless Bureaucrat in a space ship to the sun. We hear the evil Nameless shouting as he head off to destruction, demanding that a Permission to Burn Up a Spaceship form be filled out in quadruplicate.
- Dr. Useless Information, the last of the evil villains, demands that each child learn countless meaningless facts such as the capital of Angola and the anatomy of a brussel sprout (our favorite target for scorn).

Through countless hours of floortime and hundreds of stories, Jacob has developed a rich symbolic world and a high level of symbolic awareness. He understands morals, values and deeper meanings. He sees the big picture.

Recently we purchased "Throwbots," something like a graduate-level Lego kit for more advanced kids. At two for ten dollars at the local toy store it was a bargain. Jacob did a beautiful job of putting them together, in spite of the seemingly incomprehensible instructions. Upon completion we had ourselves two four-inch plastic robots that, with a flick of the wrist, tossed small Frisbees—a triumph of toy making. Naturally, for our floor time together, one robot became the good guy and the other one quite evil.

But this is where Jacob's wonderful play imagination showed its stuff. In his story, one of the robots was being programmed to keep poachers off an island. Unfortunately, the robot escapes before the programming is complete and he believes he must destroy all ships approaching the island. His lasers sink cargo vessels and ocean liners, and the passengers narrowly escape on life rafts. An epic battle is required to stop the misprogrammed and misguided robot. The unstated lesson of the play provides a wonderful insight—aggression and hostility are necessary ingredients for all of us. They are required to protect and defend ourselves against those who would take advantage of us. Yet, without the proper maturity and thoughtfulness this aggression becomes uncontrollable.

For a nine-year-old boy who is teased by his classmates because he lacks athletic ability, but who also knows is bigger and stronger than most of his classmates, the unspoken lessons of this play session are critical. He

talks about certain classmates who taunt him and imagines what he will do to extract revenge. Yet he is aware of the consequences of hurting another. He struggles with that part of him that is motivated by hostility and aggression. He accepts it as a necessary part of who we all are and seeks to keep it in check. All of these frustrations and fears are encountered and addressed within the sheltered world of fantasy play. All while having a great time. All of this is floortime.

As the years pass, it becomes easier to look back at the early days of Jacob's recovery—multiple speech therapy, occupational therapy and play therapy sessions; Tomatis, Fast For-

I was driven to heal Jacob.

ward, homeopathic medicines, highly restricted diet—hundreds of bottles of pear juice. Most of all, I think back on thousands of hours of floor time. Rebecca, Jacob's older sisters, our au pair and I were all involved and all took floor time turns. So many times friends and family told us that we should be chronicling everything, keeping a journal. We should write a book. An extraordinary story was unfolding before everyone's eyes. In retrospect, writing about it while it was all happening was probably impossible. We were too busy doing it, living it. Healing Jacob was all consuming. And that was the way it had to be. In an era of rapid solutions and instant gratification, there was no replacement for long hours and tireless effort. There could be no short cuts.

Not only was our family overwhelmed by Jake's healing, we were embraced by it. This is perhaps the most important message that I would share with parents. This isn't one priority—it is the only priority. The encompassing nature of the healing process was, in fact, what made it so powerful. It was not just about doing things—it was a matter of reframing our lives and reshaping our values. Floor time is not just a method but also a way of thinking about communication and relationships.

Looking even further back, I recall the early days of the dawning awareness of the severity of his condition. These memories are almost too painful to bring into consciousness. But they emerge. . . . Jacob's first day in

pre-school, watching him sitting in the corner, lost and terrified, crying desperately; Jacob disappearing during a visit to a sleep-away camp, the desperate search to find him and finally discovering him sitting in the cool shade under a camp bunk sifting his hand through the dirt; Jacob howling in pain after he had pulled his dresser on top of himself. These memories haunt me to this day. In spite of all our effort on his behalf, I will always wonder if I could have done more and done more sooner.

Rebecca's commitment and dedication to heal Jacob was stunning. My personal drive was obsessive. I was driven to heal Jacob. It was as much for my own well being as for his. When we learned, sometime during the early stages of Rebecca's pregnancy, that he was to be a boy, my immediate joy was soon replaced by the emergence of a wave of depression and sadness. It was not terribly difficult to figure out that I was once again mourning the death my father who passed away when I was nineteen. Jacob's birth was, at once, a realization of my dreams and a reminder of my loss. It is in this context that you must understand the devastating impact of Jake's illness, and the prospects of, in effect, losing my son as I had lost my father. And, that is how I perceived Jake's illness—he was becoming lost to me. We would never be able to communicate. I would never be able to be a father to Jacob, as my father could no longer be to me. Rather than healing the pain of my father's death, those pains, that feeling of profound loss were now re-ignited with renewed vigor.

Yet, it was this overwhelming pain and fear that propelled me forward and drove me to heal Jacob. Perhaps it was pure survival instinct. Perhaps I didn't think I could survive the loss of both father and son. I was driven to repair the damage caused by my father's death and to prevent, at all costs, the loss of my progeny. Early on in Jacob's treatment I told Rebecca that "as I healed Jacob I would heal myself." Rebecca commented, correctly so, on the danger of such a plan—the unstated reality being that Jacob just might not get better. Yet, for me, there was no option. I would not accept and I could not sustain the notion that he would not be healed. And so I was driven. And so I played with Jacob hours each day. And it was never enough. And nothing else was important. Nothing else mattered.

This perhaps is a second lesson I might

share with parents. Every parent must find his own motivation and every parent must fight his own demons. Yet, I have seen fathers and mothers who are driven *from* action rather than driven *to* it. I have seen parents paralyzed by their own fears rather than being pressed into action. I have witnessed parents who immerse themselves in broad political and social issues rather than focus on their own children. I do not minimize how emotionally difficult it is to have a child with special needs. There is a viscerally raw quality of pain, hurt and fear that a parent feels when confronted with a devastating illness of a child. I have felt it. But parents with children with serious communication disorders must somehow embrace and mobilize these feelings. The emotional presence and focus required for floor time demands it. Charting and actualizing a therapeutic and educational path cannot be accomplished without it.

For Rebecca and me, the intensity of the early days is fading. More and more, we slip in to a “normal life.” To our dismay, Jacob has become a Pokemon aficionado. He knows all the characters’ names, their powers and their attacks. He mimics their sounds and has binders filled with cards. Perhaps it is a rationalization, but Rebecca and I feel that perhaps Pokemon is not so bad for Jacob. It has provided him with an entry into the world of his

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peers. He brings his Pokemon cards to school to play and trade with the other kids. On play dates, the cards are strewn over the floor and the games begin. In the best tradition of “in for a penny, in for a pound,” we bought Jacob a Gameboy for his ninth birthday, a complete breach of the floor time ethic. (Please don’t tell Dr. Greenspan.)

Rebecca and I wonder if Jacob will ever learn of his background. At times Jacob seems to be on the verge of some awareness of his past. He is certainly aware that he is a year older than his classmates, and he has questioned why. He remembers some of the therapists. He questions why he has to participate in Fast Forward Two. We tell him it is to help him learn to read, and he accepts that explanation. We wonder if there will ever be a time that we will tell him the whole truth. Will

there come a time when it will be his right to know of his past? Will there come a point when he will reach a level of awareness that he is somewhat different? Perhaps that will be the true measure of his and our success.

Most mornings six a.m. arrives much too soon. Jacob knows he is not to wake us up before six; his arrival is more accurate than most alarm clocks. Generally, I awake to find him sitting next to me on my bed, expounding on something. Perhaps he is completing a conversation we began the evening before. Perhaps he was looking at a book before waking me and he tells me of his new discovery. I drag myself out of bed and, after a cup of coffee, I head downstairs to the den. The den is our play space—more accurately, our clubhouse. At six a.m. we are alone as if we were up in a tree. Perhaps we talk about photography or about the Civil War. Perhaps I read him Calvin and Hobbes. Perhaps we make a story with Playmobil. It is a start of another long day.

But I wouldn’t change our six a.m. time alone for anything in the world. In a moment of reflection I think back upon where we came from and what we have accomplished. In a frightening moment, I think about what might have been. I cannot imagine a father and son who love each other more. I can’t image being more proud of a child. I still don’t know if Jacob will go to MIT. If he does it will be no surprise. The memories of PDD will continue to fade. We will have long past stopped worrying about a call from a teacher. Someday, he will be one of the boys. I sip my coffee and go back to the story. It is just another day in the life of an extraordinary child.