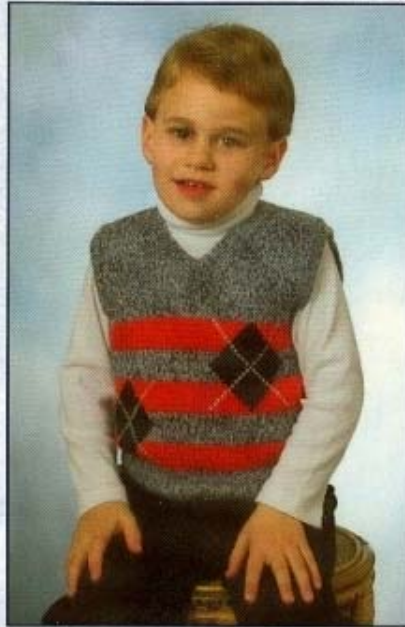


*Reflections on
Raising an
Autistic Child
for Parents,
Teachers and
Friends*



Journeying with Joshua

**By
Dr. Lois N. Spitzer**

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Finally, thanks to our families and all those whose lives have crossed our path. It does indeed take a village....

“It’s Hard to Shave a Moving Target!” (An Ordinary Day)

“What if we framed our views of the autistic dilemma in a radically different way? What if we perceived young autists as capable of shaping their lives in significant ways? What if we believed parents capable of helping them in this endeavor? What if we humanely presumed a commonality among us and them? By what moral or psychological tenets do we gloss over their agonizing struggles to relate to us?”

*(Karen Zelan, *Between Their World and Ours: Breakthroughs with Autistic Children*, page 3)*

It was an ordinary day in an extraordinary year. Joshua’s hours at work at a local grocery store as a part time bagger had changed (again), but fortunately I was on spring break from the college where I worked part time. Almost a year had passed since he graduated high school and entered into the nebulous world of post-high school life. It had been almost a year since my world has changed from the comfortable, predictable routine of his weekday school and weekend work schedule. I reduced my work hours to take on new jobs: chauffeur, job counselor, and government agency negotiator, in addition to the maternal role I have been holding for the past nineteen years.

Joshua starts work each day at 11:00 a.m. this week. Even though he doesn’t have to wake up early, he does. As soon as he

thrusts aside his blanket, Joshua seeks out our four-year-old beagle, Peanut, and hugs her so hard she cries. His intent is not to harm her, but her plaintive eyes suggest she feels trapped and threatened. I either come to her rescue or convince him to stop, or I have to pull her away from him. Either way, our tolerant pet gets mauled.

After his breakfast of his favorite cereal and milk, he plays on his computer until he is ready to be helped with his shower and dressing. I assist him with his bathroom needs because his torso is very stiff. As a result, he cannot turn well at the waist and his hand coordination is not good.

Then I shave him. He often ends up with nicks all over his face. "It's hard to shave a moving target!" is my greatest line of defense. I need to limit his shower time and coax him to turn off the water or he'll stay in the shower for a very long time. When I ask him to shut the water, his daily reply is, "It's my water!" Then I say, "Not until you pay the bills, it isn't." He replies, "Well when I have my own house..."

Does he really mean that he wants to have his own house and live apart from us? I don't think so. In fact, Joshua has told us that he always wants to live with his father and me. I think this line of conversation is his plea for some independence. How much independence? I don't know and he doesn't know. It's like a guessing game. Anyway, I can get him out of the shower only by threatening to take away a privilege later in the day like television or computer time. Sometimes I come up with a good bribe. Either one seems to work in concluding the struggle.

As he gets dressed, Joshua is full of stream of consciousness talk. He has monologues with himself about various subjects and makes commentaries on the television program that is on. Sometimes he pretends he is the newscaster and reports the news by reading the closed-captions. He sings,

shouts, and generally makes a racket in the morning, mimicking the television or just vocalizing. He alternates doing this and harassing the dog, chasing her around the house yelling, “She loves me!” When he catches her, she licks his hands and face. I have to convince him to let her go and not to get dog hair on his work clothes. He is soon satisfied to let her go, only to repeat this routine minutes later. It is obvious though that she really does love him.

I struggle to get him dressed within some reasonable period of time. All the while he is asking questions: “Why do I have to wear this? Why are you so strict? Do I have to wear a coat?” Finally, his clothes are on, and we comb his hair, which he dislikes. “Mom, you’re so fussy!” he tells me.

Then it’s off to Joshua’s job. As soon as he leaves the car and me, he forsakes his silly talk, his repetitive sounds, his yodeling, and his immature behavior and he instantly transforms into “working man.” If we’re lucky, this persona stays with him until he finishes work. If Joshua encounters something that frustrates him or annoys him, however, he is apt to lose this veneer and revert back to immature and sometimes inappropriate behavior. Does he bark at work like he does at home, I wonder? Joshua breaks into a smile the instant he enters the store. Why can’t we all feel that way about our jobs?

Most days I accompany him into the supermarket and touch base with his supervisor, always waiting for her to make a comment about his work performance. I’m nervous that his supervisor will report to me something inappropriate that Joshua has done since the last time we spoke. Today we are met, instead, by his co-workers who exclaim “Hi, Joshua!” They obviously enjoy seeing and working with him. The middle-aged women act maternally toward him, and even the younger adults treat him with much appreciated gentleness and kindness.

Joshua's simple dedication to his tasks, combined with his broad smile, inevitably melts the hearts of most of his co-workers.

With his day set, I have five hours of tranquility with which to do my work and whatever else I needed to get done. Sometimes, I even go to work myself. My daughter comes home from school at 3:00 p.m. and asks, "Why is it so quiet? Where's Joshua?" I explain that his work hours at the store have changed and he won't be home until after 4:00 p.m. "Nice!" she replies. She knows that after Joshua gets home, she will have no peace or quiet for the rest of the day.

His shift is almost over, so I leave to pick him up. He's waiting for me patiently and I ask, "So, how was your day?" He replies "E!" He means *excellent* (see the chapter entitled, "An E! Day: Autism as a Second Language"). Joshua then informs me that he had not been given nor had he asked for a break to eat his lunch. He had worked five hours without so much as a bathroom break. I would never call a day without lunch *excellent!* I'll mention that to the supervisor the next time I take him to work.

Back home, Joshua eats his sandwich and cookies and then isn't hungry for dinner an hour later. That's okay. He's wound up from work and needs some down time with his computer. I tell him he has to come to a meeting with me that night, and he doesn't complain or ask why. We never leave him home alone for more than a few minutes and never with the dog.

At 6:50 p.m., I wrench him off his computer with the promise of a snack after the meeting if he's good. Joshua accepts this offer and comes to school with me to a meeting that's in the school library. He busies himself looking at books and contentedly snooping around the library for an hour until I tell him it's time to leave. He follows me without any resistance and we stop at a convenience store on the way home to reward him

with a snack for his good behavior. He happily picks out a chocolate milk and we head home.

Once there, Joshua goes back on his computer and waits for his dad to get home from work. Lee told us it would be a late night and he has called while we were gone to let us know he'll be home around 10:00 p.m. Joshua is tired but insists on waiting for Lee before he'll even lie down. Since it's nearing 10:00 p.m. anyway, I gratefully crawl into bed.

At about 10:30 p.m., we hear the garage door open. Lee comes in, obviously tired from a long day. Joshua is waiting for him at the top of the stairs and he clumsily runs down and gives Lee a BIG hug and says, "Dad, you look tired. You need to go to bed." Lee just smiles and says, "You first." Without a struggle, he lets Lee put him to bed. Then Lee comes in to talk to me in my semi-sleep state and says his day was okay but what a great boy we have. "I know," I say.

So, now it's the next day. I have to take Joshua to work in a few minutes. He's yelling in his room and clapping wildly. Will he have an E! day today? I hope so. If he does, then I will.

A Few Days Later...

I get a call today from the store manager, Bill. "Come and get Joshua. He's upset about something." "Oh no," I think to myself.

I run over to Joshua's store and Bill reports that Joshua had been running around the parking lot, ostensibly collecting carts, but instead yelling (at the carts) and ramming them into the stalls. At one point, he was running backwards with a cart and he collided with a car that was pulling out. Joshua had hit the car with the back of his body, not the cart, and he had a big black

mark on his pant legs. The driver of the car was very upset and walked back into the store with Joshua to tell the manager what had happened. Bill asked Joshua to lift his pant leg to make sure his leg wasn't injured. It was a little red but there was no blood or bruise. The woman left, visibly shaken.

Bill then took Joshua aside and asked him what had happened. Joshua's response was, "I backed into the car." He asked why and all Joshua could say was, "I don't know." Bill was inexperienced with my son's occasional peculiar behavior. Frustrated by Joshua's inability to communicate with him, Bill called me. Actually, I was grateful he called, and I told him so. Joshua was probably upset or set off by something, I explained, which he could not express and this happens occasionally. I commended Bill on the way he handled the situation and told him that Joshua just needs some time by himself in a quiet room for a few minutes when he behaves like this to collect himself.

Bill seemed to understand and was willing to give Joshua a break to calm down. I certainly hope this doesn't happen again. I felt embarrassed for Joshua and sympathetic toward Bill, but I know it will happen again. I just hope Joshua doesn't hurt himself next time.

Staring at Windmills

If you ask me to describe the past 19 or so years in a few words, they would be always *challenging* and oftentimes *rewarding*. Joshua has brought to our lives an incredible delight and a totally new way of looking at the world. The journey has presented lots of challenges that have tested us to our limits. Would we trade him in for a different child? No way! Without Joshua, our lives would not be as rich, wonderful and, at times, hilarious as they are.

This set of reflections is an account of the many positive and funny experiences and also the challenges we've faced; we seek to give the reader ideas, strategies and suggestions as to how to meet the needs of special individuals and hopefully understand them better.

I know that no child comes with an owner's manual. (Wouldn't it be nice if they did?) The closest I've ever come to one is a short piece by Emily Perl Kingsley titled "Welcome to Holland" (1987). Kingsley begins: "I am often asked to describe the experience of raising a child with a disability- to try to help people who have not shared that unique experience to understand it, to imagine how it would feel."

She explains that planning for the birth of a child is like planning a vacation to Italy. You read up on the country and you make preparations based on what you have learned by those who have traveled to Italy before you. During your voyage, or the day you give birth, or in some cases, the day the child is diagnosed with a disability, you learn that instead of arriving in Italy, you have instead landed in Holland. You protest that this is

not where you wanted to go or where you planned to go. But you learn that there you must stay. You didn't bring the right clothes, learn the right language or make the right preparations.

Kingsley says that the important thing to realize is that you haven't arrived at a bad place, it's just not the place you thought you were going and you feel unprepared. "But everyone you know is busy coming and going from Italy...and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say 'Yes, that's where I was supposed to go. That's what I had planned'... But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things...about Holland."

I remember reading that piece and feeling, "That's how I feel - totally unprepared!" It was as though I thought *I* was going to see cathedrals but instead found myself staring at windmills!

I have been asking myself: "How are you going to describe this experience?" For a long time, I have wanted to talk or write about raising an autistic child but I've never been able to decide upon exactly what I wish to say. Recently, it came to me. I want to describe the way it *feels*. I want to describe how I have changed, or rather how the experience has changed me. I want to describe that as-deep-as you can get gut feeling. The feeling is not always good but sometimes it's good beyond description. And sometimes it's frustrating and angry. It *is* what I feel. And perhaps by sharing my feelings with you, I can let you know that whatever you're feeling is part of the journey of raising an autistic son or daughter.

I have come to understand that this journey touches everyone involved. It is not mine, his father's, his sister's or his alone, although they all have stories to tell. At the risk of sounding trite, we're all in this together.

It amazes me to realize how many lives my son has touched. If he were a different child, this would not be the case. He is who he is and I love him as he is. I am a better person because of him and so is everyone with whom his life intersects. So, the focus of this story is to tell you about Joshua and my journey through autism, his world, and how I have come to appreciate not only visiting, but living as a resident of Holland.

Before Holland...

Going back to the time before Joshua propelled us toward Holland, Lee and I were born in 1957 and 1958, respectively. Our family lives were nothing that resembled what you would think of as a normal childhood. Lee's mother died when he was thirteen and he was raised with his two siblings by his father. I lost my mother to a car accident when I was eleven, and my father died when I was twelve. I lived with various friends until I went to college.

Lee and I married in 1977, when I was eighteen and he was twenty. We moved to California so Lee could attend seminary and I could finish my undergraduate work. We then moved back to the East Coast in 1979 and in 1981, Lee accepted his first call as an American Baptist pastor for the First Baptist Church of East Providence, Rhode Island.

We intentionally waited for seven years after we got married to have children, and I think the congregation thought perhaps there were medical issues preventing my pregnancy. One elderly member even told us that she was praying to see our first child before she died! They all seemed relieved when I got pregnant; little did they know I actually conceived very quickly.

Joshua was born in Rhode Island on March 25, 1985, and we were supported there by a very loving congregation. Lee was the youngest pastor they'd had in awhile, so when Joshua was born, all the parental and grandparental instincts of the church members came out in full force. Joshua was the darling of the congregation.

In 1986, we felt a call from God to serve in another church. This time we felt led to accept a pastorate in southern New Jersey, where we were then embraced by the congregation of Seaview Baptist Church in Linwood. Larisa, Joshua's sister, was born while we were serving there.

We truly loved living in New Jersey, and especially enjoyed the Jersey shore. Since Lee and I had both grown up on Long Island (New York), we had been raised near the water. Living only a few miles from the beach and boardwalk in Ocean City was truly a delight for us. I brought Joshua and Larisa to the beach when they were still in diapers and they grew up with sand in their hair and sea water on their skin. We spent so many beautiful days at the 24th Street beach, which was south of the Ocean City boardwalk.

Then, in 1994, we received a call from a church in Lincoln, Nebraska. Nebraska? At first our response was, "No way!" But God had other plans for us. So, two New Yorkers decided it was time to experience the Midwest and we packed up our house and our kids and accepted a call to First Baptist Church in Lincoln.

Again God provided with a wonderful and caring congregation who embraced us and showed us the best the Midwest has to offer. We were surrounded by beautiful prairie and enjoyed a more relaxed pace (by our standards at least) for nearly ten years. Joshua received a superb education given by

commensurate professionals who embraced him and us. Our years in Nebraska will always be remembered with fondness.

Since God is always keeping us on the move, true to form, Lee was nominated for the position of executive minister of the American Baptist Churches of New Jersey. In January 2003, he received the call to serve as the pastor of the region's two hundred and seventy-three churches, and he accepted it. We were so excited about the prospect of moving back to the East Coast. As much as we loved the people in Nebraska, we missed the ocean and our friends and family back East.

Lee moved to New Jersey at the end of February 2003 and left me and the children in Nebraska to finish out our school years and sell the house. For four months, we were separated and then finally in July 2003, we moved into our new home in Bordentown (New Jersey) and our family was reunited.

I have also been working all these years, mainly as an educator. I finished my undergraduate education in California with a bachelor's degree in French, earned a Master of Education in English as a Second Language from Rhode Island College and a Doctorate of Education in Applied Psycholinguistics from Boston University. Had I known that I was going to have a child with a language delay, I would have concentrated my studies on first language acquisition, but one never knows what the future holds. Holland wasn't yet in sight.