

Chicken Soup for the Soul®

101 Inspirational
Stories for
Parents of Children
with **Autism**
and **Asperger's**

Raising Kids on the Spectrum

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Beacons of Hope

*Anything I've ever done that ultimately was worthwhile...
initially scared me to death.*

~Betty Bender

It all began so unexpectedly with a trip to Barnegat, New Jersey, where we were visiting friends who suggested a trip to the local lighthouse. Why our son, Ben, was so attracted to “Old Barney” is still a mystery. He made a beeline for the door and flew up the stairs with my husband on his heels. Our older son, Alex—who was extremely afraid of heights—refused to make the climb. I was more than happy to sit this adventure out.

I should have known my persistent little boy was not going to let me off so easily. Having flown down the stairs as quickly as he had raced up, Ben announced he was ready to go again. My stomach churned with each vibration of the metal staircase under my feet as I raced to keep pace. What propelled me up those stairs was fear. My adrenaline-addled brain manufactured images of Ben flying over the railing at the top. Autism is not for the weak-hearted.

I caught my breath as we passed through the door together. The wind was whipping ferociously as I paused to deal with my jelly legs, still shaky from the exertion of the climb. With my back pressed to the wall, I eased my way to the far side of the observation deck. When both the air and the shaking stilled, I took in the view and shared what he saw.

Magic.

His beaming smile was pure joy as his eyes met mine briefly before focusing again on the horizon. For a moment, we were connected by the intensity of his experience, his elation. It was hard to remain afraid of something that captivated him so totally. These are the moments I live for. As elusive as they can be, these connections are possible in the most unexpected of moments.

The following summer, we visited the old Cape Henry Lighthouse in Virginia Beach. We decided to take an early morning climb before the day's heat became too oppressive. When we arrived, we were the only visitors there and I recognized an opportunity to try the climb with Alex too. If he got angry and had a tantrum over the suggestion that he try the climb, we had the privacy to work through it with him. So many of Alex's fears at that time in his life were not based on real factors as much as they were about sticking to routines and not taking risks. After many years of tag-team parenting, Joe and I were beginning to realize that we needed to do more things together as a family. I suggested to Alex that maybe he could try.

"I AM NOT GOING UP!" The screaming was blood-curdling and he dropped to the ground and kicked for several minutes.

I waited for the storm to pass. He became quiet and stood back up, so I continued: "There are times we do things for Alex, and there are times we do things for Ben. Ben always goes to the aquariums with you and tries the things you like. Now is a time when we do something for Ben. This is what families do; they take turns."

Alex dropped back to the ground and yelled some more. "It sure is hot," I continued, as I sat down on the floor near him, deciding that I had reached a point of no return. We had long ago decided that tantrums like this would not deter a request; this would only reinforce his tantrums as a means to avoid an unpleasant task, so I decided to sweeten the deal for trying. "As soon as we're done climbing up, we'll go back to Grandma's and go in the pool."

I had his attention now. "Do you want the pool?" I asked.

"YES!" he said.

"Well, let's climb up and get it over with, okay? First we climb, then we swim."

"YOU ARE THE WORST MOTHER EVER!" he screamed.

"Alex, if you really, really hate this you will never have to climb up another lighthouse again. I promise. You'll never know if you don't try."

"Alright, alright! But then we are swimming!" He stood up, approached the stairs and took a step.

"Good job, Alex, I'm right behind you!"

The 191 steps to the top were in some respects the hardest I have ever taken. I second-guessed myself, wondering if I had pushed too hard. The verbal assault continued the entire way up, and I couldn't help but notice that my boy had a knack for constructing beautiful sentences when he was mad, a stark contrast to years earlier when he was losing words at an alarming rate.

As Alex stepped onto the deck of the lens chamber from the opening in the floor at the top, I heard him draw a breath in sharply. I prepared myself for the worst.

"Wow," Alex admitted. "It's great up here!"

Magic.

When we reached the bottom and made our way outside, I posed the boys in front of the lighthouse and snapped a picture of them, both smiling, arms wrapped around each other in a moment of tactile tolerance.

"Alex, I am going to put this where you can see it at home, because I always want you to remember how awesome you are for overcoming your fear! There is nothing you can't do as long as you try!"

His eyes darted to mine before slipping away; his voice caught as he tried to hold back his tears. Before I knew it, I was receiving a very rare hug.

"Thank you for making me do that, Mom. Thanks for making me go to the top."

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Six years later, we have climbed more than twenty structures across seven states, including a weeklong trek to the Outer Banks to climb

the Cape Hatteras Lighthouse, which is the tallest in America. Alex and Ben handled the changes in routine and unfamiliar surroundings on that trip better than we had ever hoped, no doubt because of the role the lighthouses played.

Many of our successes are wholly dependent upon how we choose to view the challenges autism presents. What if, along the way, we had decided that Ben's lighthouses were truly a negative "perseveration" that we somehow needed to quell or otherwise control because the intensity was out of whack with what might be considered "normal"?

Instead, by joining Ben in his interest, we grew together as a family. By pulling Alex out of his comfort zone and into his brother's, we have given him a powerful memory to sustain him in the frightening moments when he has to try something new. In these beautiful, enduring structures, climbing with other enthusiasts, people who meet Alex and Ben don't see two boys with autism. They just see two boys who share their love of lighthouses. They are a helpful, hopeful symbol to me, linked to both of my sons' continuing triumphs over autism in so many ways.

~Christine Bakter



Do Dogs Have Autism?

You don't choose your family.

They are God's gift to you as you are to them.

~Desmond Tutu

“Mama? Do dogs have autism?”

“I really don't know... but that's a very good question, Lil.”

It really was a good question from my seven-year-old. Lily is an interesting girl. Headstrong, independent, so full of joy and energy that at times it can turn on her, making her restless and obstinate. She knows what she wants and isn't afraid to tell you. Of all my kids, she is the most like me in temperament, which sometimes makes her my most difficult. Have you ever tried to butt heads with yourself?

We were new to all things autism when Lily was an infant. I used to worry that I wouldn't ever be able to give her enough time, energy, attention. That somehow, because her brothers' needs seemed so enormous, hers were going to be put on the back burner. It took me about five minutes to get over that. Lily never saw autism. Instead, she saw her brothers—her competition. To her they were all on equal ground. If she wanted attention she learned how to get it. I don't mean that in a negative way. It's more like she sees herself as any sibling does. The parents are fair game and if you want something from them you jockey for position to get it. She does a very good job.

So although I wasn't surprised by her question, it was the

reasoning behind it that made me think. “Autism” is a word that we use at home. Our boys are of an age where they notice that they are different. So we have been very open with our kids—how could we not? Lily, however, sees this as her brothers and little sister having something she doesn’t. “Sam has autism?”

“Yup.”

“Oscar has autism?”

“Yup.”

“Zoe has autism?”

“Yup.”

“So they all have autism and I don’t.”

“Yup.”

“Well that’s not fair! What do I get?”

“A big hug and kiss from me?”

“Maaama!”

We have always talked to the kids about how people are different, and that some people by their behavior or words or lack of words might appear more different than others. But no matter what the differences, everyone was deserving of dignity and respect. Everyone. We didn’t use the word “autism” until we saw it on the television show *Arthur*. You know, the show where the lead character, Arthur, is an aardvark? It wasn’t as if I was ashamed of the word. It just needed to be put in a way they could all understand. Sigh... sometimes, I guess it doesn’t take a village... sometimes it takes an aardvark.

All of my kids require some sort of accommodations. All of them, and yes, some more than others. (We are a great example of what a spectrum is.) That’s just the way it is. I don’t weigh one against the other, assessing the degree of need. They are my children and they are equal.

So, do dogs have autism? I couldn’t tell you. What I said to Lily was, “Would it matter if they did?” She thought about it for half a second.

“I guess not.” The conversation was left at that. She was already off and running on to the next thing that caught her interest. Because autism doesn’t really matter to her. She looks at our family and sees

just that—her family. Where she knows she is loved and cherished for being who she is. A sister and a daughter who sometimes thinks she is queen. She gets that last part from me.

~Kathleen Leopold



Autism Does Not Define Me

*To be nobody but yourself in a world which is doing its best night and day
to make you like everybody else means to fight the hardest battle
any human being can fight.
~e.e. cummings*

Accept me for who I am.
Understand that I may not always get what you're saying.
Trust that God has me here for a reason.
I am an amazing human being.
Socially, I might not fit in with society's expectations.
Mentoring can help me along the way.

Don't forget that I have feelings even if I don't express them.
Opportunities for my happiness are indeed possible.
Educate and encourage me without prejudice.
Show patience and kindness along the way.

Never give up trying to "get" me.
Ostracizing me will just shut me down.
Take time to try and come into my world.

Defining me as my diagnosis ignores my essence and best qualities.
Emerging talents may arise when you least expect them.
Friendship and honesty is valued to me more than you can imagine.
I am in need of love and tenderness too.
Never let me give up, especially when you see my mood shift.
Expect the unexpected and watch me enrich your life.

Many people will read this and I pray millions will act.
Embrace and empower someone with autism today.

I originally wrote this poem on April 8th, 2010. My sons Justin and Ryan were ten and three at the time, both having been diagnosed on the autism spectrum in 2008.

Ryan was diagnosed first with autism when he stopped speaking around eighteen months old and a variety of behaviors changed. We did a tremendous amount of research about autism and Asperger syndrome and realized that our older son, although he didn't have the speech challenges of our younger son, had his own set of issues. Both children also had many sensory processing challenges. Justin was diagnosed a couple of months later with Asperger syndrome. Later, at an autism conference, I met some adults on the spectrum, including a couple of women (who present differently) and a light bulb went off in my head. I had been living for over forty years as an undiagnosed Aspie.

At the time I wrote "Autism Does Not Define Me" I was fulfilling a pledge to blog once each day during Autism Awareness Month in April. That particular day I felt an overwhelming connection with both Justin and Ryan. I wanted them to know that they have my full support in being who they are and I wanted to remind them that who they are is not defined by a word.

It wasn't long after I wrote the poem that I founded a non-profit public charity called Autism Empowerment, which launched in June 2011. Our four foundational pillars are Accept, Enrich, Inspire and Empower and we share a message of positivity and support locally,

regionally and around the world through Autism Empowerment Radio and the development of inspirational programs and services.

~Karen Krejcha

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