



The Joys of Autism

By **Melanie K. Milicevic**

MOST PIECES I WRITE ARE ABOUT MY FRUSTRATION WITH HOW CHALLENGING IT IS TO RAISE A SPECIAL NEEDS CHILD IN THE SPACE WE LIVE IN TODAY. THEY ARE ABOUT FIGHTING THE EDUCATIONAL SYSTEM, THE LACK OF SUPPORTS FOR FAMILIES, OR MY STRUGGLES DUE TO MY INADEQUACIES. I ATTEMPT TO SPEAK MY TRUTH IN AN AUTHENTIC WAY, AND WHILE I UNDERSTAND THAT'S ME SHARING MY VULNERABILITIES AND WEAKNESSES, I ALSO RECOGNIZE SOME WOULD INTERPRET THIS AS A WHOLE LOT OF WHINING.

But raising a child on the spectrum (or an autistic child, whichever you prefer) is also a great joy. I want to highlight some of those precious moments now. I often tell people, “Everything I’ve learned about life is because of autism.” So, autism is actually my greatest course of study in my lifetime, and my son is the most important professor I’ll ever encounter. It’s the most rigorous degree I’ve ever attempted to complete. And though I’ll never actually get a “degree,” I continue to reach for knowledge, wisdom, and hopefully a more humble, intelligent perspective.

The first joy came because of the people who entered my son’s life early on. They became our family. It’s an interesting phenomenon, and many hard-learned lessons have come from it. The people you expect to be there in the beginning are not there. They somehow fail. They say, “We don’t know what to say. We can’t make it better. We are so sorry.” And then they walk away.

You’ll never see those family members or friends the same way you did before. When someone fails you at the most vulnerable time of your life with your child, you have that permanently etched into your brain. Every time you see them for the rest of your life, you’ll remember the unkind words, how they walked away, or their insensitivity to you, your spouse, or your kids. The fact that they never once asked, “Can I do something? What do you need?” will poke at you. And worse yet, when you do ask them to accommodate you, they don’t. I remember asking people, begging actually, “Please just come over and play with our kids. Bring your kids over to run with them and interact and make us feel human.” They didn’t show up.

Then, in came this flood of angels. They don’t look like angels at all. They look like Applied Behavior Analysis (ABA) therapists, speech and occupational therapists, supervisors, social workers, and teachers. They are professionals, moms, or recent college graduates. They are not your family by blood, and sometimes, you even push them away. But they are your new family. They will know you and your immediate family better than your other family. You will be raw with them, there will be shared tears, and you will realize they’ve appeared in your life where this large aching hole existed, the one that formed because all your friends walked away from your pain because it was too much for them to dive into.

These new angels will soothe your unbearable pain by loving your child more than you ever knew possible. I still call these people my family. I will never forget the Chelseas, the Sarahs, the Sandis, the Jordans, the Alyssas, and the Tinas. These women became my sisters. I am so grateful for them and always tell them, “You saved me.”



Every so often, you get someone exceptional, a life changer. I remember Sarah often because she was our toughest ABA therapist. She adored my son, spoiled him with intense love, and she was a blast. But that fierce woman pushed us all farther than we ever wanted to go. There were times she broke us, but in the end, she taught me how to parent. She taught me to have the highest expectations and let go of some things I still struggled to release. I will never forget her, and even though she’s one of many, I remember her often, and I am thankful my son had the opportunity to learn from her for many years. Sarah is a legend.

The next joy came in the form of special needs families and support groups. Many families came in and loved us at a time we desperately needed it. They gave us words of encouragement, advocated for us in Individualized Education Programs (IEPs), or cried when we couldn’t get out of that black hole of grief. These mothers, friends, special needs buddies (namely Josh), and special agents of autism saved us. They gave us hope when we couldn’t move an inch forward.

Sometimes they gifted us free event tickets, which gave us the courage to try something new with our kids. It was often tickets to something we might have been afraid to try (like Disney World) due to the cost, the crowds, and the sensory overload. These gifts were worth much more to us than the money we saved. They were opportunities. Doors opened that we weren't brave or strong enough to try opening ourselves due to constant fear and the fight or flight state we lived in for years.

My last joy is always his words—the words my son speaks to me are my hope and pride. Hearing his voice is truly my greatest joy. I am one of the fortunate parents who saw language bloom early on. We worked hard for every word, though. It didn't begin like this. He had very unusual language for many years. Scripting, echolalia, more scripting—it took forever for him to learn things like hellos and good-byes. Answering questions took years and years. But we

never gave up, and he never stopped trying, and something about that combination worked.

Something about being relentless in our quest for words finally sank in. My son got it, and not just that—he now speaks like a champion. Each time he talks to me, I fill up with so much joy, hope, and gratitude because I remember what it felt like when he was lost inside himself and unable to communicate with us. I remember those scared eyes, his melt-downs, and my feelings of grief and fear, which consumed me every moment. The joy for me is hearing him, seeing him communicate well, and knowing these gifts are truly the greatest rewards I will ever be given. I am not worthy of them, but I embrace them wholeheartedly. And I'll never give up on hoping and praying that every special needs parent is given the gift of progress. I pray every family with similar struggles can and will feel these joys.



*Melanie K Milicevic is a graduate of UCLA and a former fifth-grade teacher for the Los Angeles Unified School District. She mainly worked with second language learners and collaborated with special needs families to meet the unique needs of her students. She now advocates for her own special needs children and continues to work with schools to help educate them about ways to include children of all abilities in the classroom. Melanie is a passionate writer and has been published in *Autism Parenting Magazine*, *Exceptional Needs Today*, and *Special Needs Resource Foundation of San Diego*. She lives in San Diego with her husband and two children.*



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