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PERSPECTIVE

I'm Focused on Accepting My Daughter's Autism — Not a Cure

By Shanon Lee — <u>Updated on April 18, 2019</u>

Everyone is preoccupied with curing my daughter's autism. I'm focused on fighting for her acceptance.



Health and wellness touch each of us differently. This is one person's story.

Staring into my newborn daughter's eyes, I made a vow to her. No matter what happened, I'd be her biggest supporter.

More of her personality was revealed as she grew. She had quirks I adored. She hummed constantly, lost in her own world. She had an unusual fascination with ceilings and walls. Both made her giggle.

As a toddler, her obsession with random body parts placed us in embarrassing predicaments. We still laugh

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She also had quirks I couldn't stand.

At one point, her aquaphobia became nearly unmanageable. Each morning became a battle to get her dressed and ready for the day. She never adapted to a daily routine, or ate regularly. We were forced to give her nutrition shakes and monitor her weight.

Her preoccupation with music and lights became time-consuming distractions. She was easily frightened and we had to vacate stores, restaurants, and events abruptly without warning. Sometimes we weren't sure what triggered her.

During a routine physical, her pediatrician suggested we have her tested for autism. We were offended. If our daughter had autism, surely we'd know.

Her father and I discussed the doctor's comments on the car ride home. We believed our daughter was quirky because her parents are quirky. If we noticed any small signs then, we chalked them up to her being a late bloomer.

We never stressed over her early setbacks. Our only concern was keeping her happy.

She didn't grasp language quickly, but neither did her older brothers. By age 7, her older brother had grown out of his speech impediment and her youngest brother finally became vocal at age 3.

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Fighting for my daughter's acceptance

I was so suppressed growing up as a military dependent, I wanted to give my children the freedom to grow without placing unreasonable expectations on them.

But, my daughter's 4th birthday passed and she was still behind in development. She'd fallen behind her peers and we could no longer ignore it. We decided to have her assessed for autism.

As a college student, I'd worked for the Autistic Children's Program in public schools. It was hard work, but I loved it. I learned what it meant to care for children that society would rather write off. My daughter didn't behave like any of the children I worked with closely. Soon, I found out why.

Girls with autism are often diagnosed later in life because their symptoms present differently. They're skilled at masking symptoms and mimicking social cues, which makes autism harder to diagnose in girls. Boys are

diagnosed at a higher rate, and I often worked in classrooms without female students.

Everything began to make sense.

I cried when we were given her official diagnosis, not because she had autism, but because I glimpsed the journey ahead.

The responsibility of protecting my daughter from harming herself, while protecting her from being harmed by others is overwhelming.

Each day, we work hard to be attentive to her needs and keep her safe. We don't leave her in the care of anyone we cannot trust to do the same.

Though she's happily settled in preschool and has blossomed from a timid, quiet girl into a bossy, adventurous one, everyone is preoccupied with fixing her.

While her pediatrician encourages us to investigate every possible program known to man for children with autism, her father researches alternative treatments.

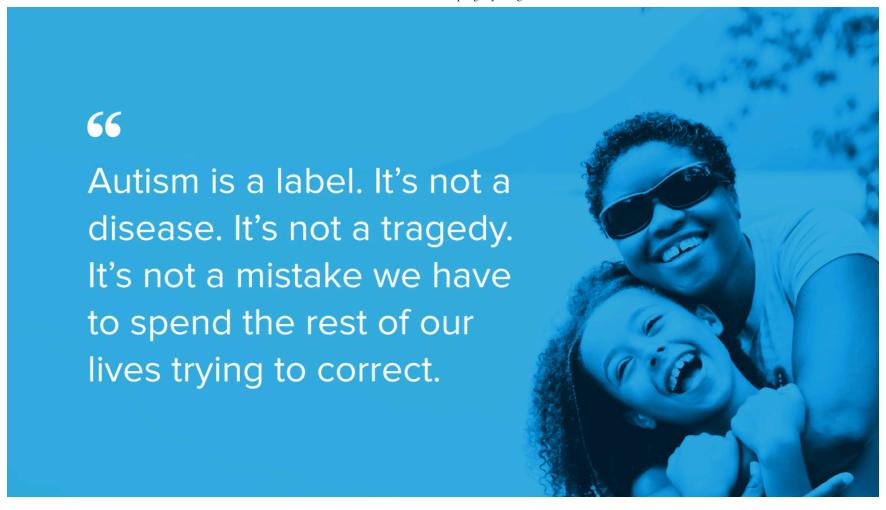
Our home is stocked with various supplements, alkaline water, and any new natural treatment he finds out about online.

Unlike me, he wasn't exposed to children with autism before our daughter. Though he has the best intentions, I wish he would relax and enjoy her childhood.

My instinct is to fight for her acceptance, not try to "cure" her.

I'm not bearing any more children and I don't want to undergo genetic testing to try to figure why my daughter is autistic. We can't do anything to change that fact — and to me she's still my perfect baby.

Autism is a label. It is not a disease. It is not a tragedy. It is not a mistake we have to spend the rest of our lives trying to correct. Right now, I'm only willing to initiate therapy that helps improve her communication. The sooner she can advocate for herself, the better.



Whether we're fending off the concerns of grandparents that don't understand her developmental delays, or are making sure her needs are met at school, her father and I are vigilant about her care.

We contacted her school principal after she arrived home from school with unusually cold hands. An investigation revealed that the classroom heat failed that morning and the teacher's aides neglected to report it. Because our daughter cannot always communicate what's wrong, we have to do the work to identify the problem and resolve it.

I don't attribute all of her personality traits and behaviors to autism, knowing many of the things she does are typical for her age group.

When her father revealed her diagnosis to a parent who had reacted angrily after she bumped into their child at the playground and kept running, I reminded him that children between the ages of 4 and 5 are still learning social skills.

Like her neurotypical siblings, we're here to give her the tools she needs to be successful in life. Whether it's with additional academic support or occupational therapy, we have to research the available options and find a way to provide it.

We have far more good days than bad. I birthed a joyful child who wakes up giggling, sings at the top of her lungs, twirls and demands cuddle time with mommy. She's a blessing to her parents and her brothers who adore her.

In the early days following her diagnosis, I grieved over the opportunities I feared she may never have.

But since that day, I've been inspired by the stories of women with autism I find online. Like them, I believe my daughter will get an education, date, fall in love, marry, travel the world, build a career, and have children — if that's what she desires.

Until then, she will continue to be a light in this world and autism will not stop her from becoming the woman she's meant to be.



Shanon Lee is a Survivor Activist & Storyteller with features on HuffPost Live, The Wall Street Journal, TV One, and the REELZ Channel's "Scandal Made Me Famous." Her work appears in The Washington Post, The Lily, Cosmopolitan, Playboy, Good Housekeeping, ELLE, Marie Claire, Woman's Day, and Redbook. Shanon is a Women's Media Center SheSource expert and an official member of the Speakers Bureau for the Rape, Abuse and Incest National Network (RAINN). She's the writer, producer, and director of "Marital Rape Is Real." Learn more about her work atMylove4Writing.com.



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