

VIEWPOINT

Mother-son duo with autism bond through their differences

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“Elijah is a different drummer!” my father-in-law yelled about my 2-year-old son one evening when I was over for dinner. I loved my in-laws, but I was incensed to learn that they had just visited a school for young children with disabilities and concluded that Elijah needed to be evaluated. They recognized something I hadn’t yet: Elijah has autism.

A few months later, Elijah began having seizures. In the weeks that followed, he went through a battery of neurological tests. The results showed severe to moderate delays in all developmental arenas. At age 3, Elijah entered an intensive training program to develop his speech. By age 4, professionals were describing his behaviors as “autistic-like.” I saw myself in a new way — as a parent of a child with a disability.

A full 11 years later, I discovered that I have the same disability.

I now write and teach others about disability services. I also direct the **Autistic Global Initiative**, where I promote research, education and awareness of adults with autism. But I have always floundered in many ordinary situations.

Yet there were upsides. Sharing traits with Elijah meant I ‘got’ him. I understood his sensory challenges, and we relished our restricted interests. Most of all, without Elijah, I never would have recognized who I was — a woman with autism who had pretended to be normal for much of her life.

Fuzzy hunting:

Even before our diagnoses, it should have been obvious life was different for the two of us. When Elijah was a toddler, he spent a lot of time focusing on minute details. For example, he would pull tiny, nearly invisible fibers from his pajamas, often for hours, while on my lap. I called this activity “fuzzy hunting,” and I confess that I was just as enthralled as he was, watching and cheering him

on in a whispering voice so as not to break his concentration. Fuzzy hunting calmed Elijah, a sensitive toddler who was prone to high-pitched screaming, never napped and always had to be in motion but for these periods of intense focus. It calmed me, too.

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Long after Elijah had been diagnosed, **Stephen Shore**, professor of special education at Adelphi University in New York and a friend on the spectrum, described that mutual calming as “co-regulating.”

By then I was beginning to see that I shared strong affinities with the adults with **Asperger syndrome** I'd met at the disability conferences I attended for my work. By the time I was 40, I suspected I was what a fellow advocate with autism, Jerry Newport, called an APHID, or ‘autistic parent heavily in denial.’ My three closest friends were all on the spectrum, yet whenever I considered evaluation, I told myself I didn't need services, so what was the point?

But that same year, in 2003, I had a crisis. I had left my teaching position in German literature to start a school for kids with autism. The shift from predominantly solitary, intellectual work to a management role with 10 staff threw me into a tailspin. My lifelong insomnia and anxiety became extreme, and I struggled with the high volume of social interactions with students, parents and teachers.

Liberated from pretending:

That's when my dearest friends insisted I get evaluated. I enrolled in a study at New York University focusing on the social cognition of adults with **Asperger syndrome**.

Over the course of half a day, a research clinician gave me the **Autism Spectrum Quotient** (a questionnaire) and a clinical interview. Someone also interviewed my mother by phone, asking her about my behaviors as a child and the age at which I met developmental milestones. I was sized up against standard indexes of empathy, social **anxiety** and obsessive-compulsive disorder. When the evaluation was over, I walked to my car, got inside and wept. I sensed my life was about

to change.

I met the criteria in all five areas needed for a diagnosis of Asperger syndrome (a subtype of autism that has since been **subsumed into autism**). The signs are particularly evident in my social skills — my unusual eye contact, flat tone of voice and difficulty showing my feelings to others. I am intensely preoccupied with niche subjects, such as tornados and the history of Negro Leagues baseball. I also have motor and sensory processing difficulties. The diagnosis was a relief. It liberated me from the limbo of pretending.

Popular girls:

I grew up with three sisters, all close in age. Popular girls, they paved the way for me socially. Watching them curl their hair and put on makeup while they talked about boys taught me how to ‘pass.’ I learned how to mimic what was necessary to get through the day and to maintain my friendships. This kind of mimicry is a common coping strategy for women and girls on the spectrum.

Despite my sisters’ help, I still struggled socially. In high school I took long walks on the prairie of Pueblo, Colorado, where I was raised. There, I would assiduously review my social interactions at school that day, repeating everything I had said, trying to divine whether I had committed a faux pas. I do the same today when I am going through difficult periods with coworkers or close friends.

As an undergraduate at the University of Colorado Boulder, I had just one close girlfriend. After Russian class, we would hike in Boulder’s lovely foothills, conjugating verbs for each other in the other foreign languages we knew — French, German, Dutch, Spanish. We spent hours comparing the rules and exceptions of the pronoun systems of these tongues.

Being Elijah’s mom was similarly isolating. I could not connect with the other mothers in our hometown of Woodstock, New York. No one spoke to me at the public library when we went to children’s story hour, and the other children didn’t play with Elijah because he was too busy inspecting the old projector gathering dust at the back of the room. When I tried to bring him to the big carpet to listen to the librarian read books, he let out a bloodcurdling scream. “We all hated it when the two of you showed up at story hour,” a parent confided after our children were grown.

I had few sources of support. Not a single book exists for people on the spectrum about how to be a parent, and I was reluctant to share my diagnosis at support groups for parents of children with autism for fear that the others would not take me seriously, or worse, consider me incapable of parenting my child. Then as now, I got my guidance from people like me — mothers on the spectrum of children on the spectrum.

Stage mom:

It's been 12 years since my diagnosis. Knowing about myself helped me be a better mother to Elijah. When he left high school, I was attuned to the **monumental struggles he faced** with employment and social relationships. **Dena Gassner**, founder and director of a New York-based advocacy organization called the Center for Understanding, says, "When parents know they are autistic and they embrace their identity, they can be more intuitive and strength-driven in understanding their child's needs in a way that may be enhanced over the capacities of non-autistic parents."

And from that strength lovely things can grow. Elijah's narrowly focused interests may have been tedious at times, but they were usually compelling to me. We discovered many treasures over the years, from fuzzy hunting and a deep preoccupation with Yosemite Sam to a comprehensive review of the oeuvre of Laurel and Hardy. We even went on the road together when Elijah began to study acting and perform stand-up comedy, leading to an appearance on MTV's "True Life." I was the stage mom; he was the talent. We made a great team.

The other night, on the phone, Elijah and I tossed around lines from comedies such as "Talladega Nights" and "Borat," and made sarcastic jabs at each other. "My wife, she die. High five!" he said, laughing, imitating Sacha Baron Cohen. Then, realizing it was past midnight, we said we loved each other and hung up the phone.

I suppose Elijah is a different drummer. But if that's true, so am I. When autism is in the fabric of a family, just who is different remains a matter of perspective.