



By Caryn Sullivan

AUTISM AND THE STRUGGLE FOR ACCEPTANCE

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Today is World Autism Awareness Day, designated by the United Nations as a day to increase knowledge about autism as well as to inspire compassion, inclusion and hope. I salute the millions of parents with children on the Autism Spectrum who share my struggles, yet embrace strategies and beliefs as disparate as the characteristics of those on the spectrum.

Many will engage in efforts to raise awareness about the condition and the importance of diagnosis and intervention. Locally, parents and professionals, ever more organized and focused, will gather at the Minnesota Capitol to educate legislators about pending legislation and to seek their support for bills that address lifesaver technology, insurance coverage, and seclusion and restraints in schools. Similar efforts are under way across the nation as a growing need and sense of urgency beget action and advocacy.

These days, I find myself focusing on acceptance, an important component of the process that garners little attention, particularly when parents are consumed with the cure, as I was. For years, I desperately devoted most of my time, energy and resources to snatching our son from the jaws of ASD.

One day, he overheard me talking with a scientist friend about the potential causes of and cures for autism. Indignantly, he said to me, "Autism is not a disease ... it's a condition." It struck me that he knew himself better than I did, and he was drawing a line, saying, "This is who I am. Don't try to fix me." His statement haunted me, forcing me to ask myself what I was trying to accomplish.

In time I understood he is first a person and secondly a person with autism. For him, that means he has a condition that affects his ability and desire to sustain interpersonal relationships, to execute tasks that are second nature to most, to control his attention, energy and emotions — and more.

That insight was my salvation. It helped me to stop fighting the invisible demon. Disengaged from the fight for the fix, I have instead focused on doing the same for him that I have done for his siblings. I am helping him to develop an unknown potential by giving him the best education we can obtain for him, as well as the support he needs to develop the skills that will optimize his chances for leading a fulfilling life.

Taking his lead, I have morphed from a parent determined to fix her child so that he was like his older brother — smart, athletic, engaged in the world and with the people around him — to one who has mostly accepted him as he is. We will never have engaging

conversations about books, politics or blogging as I do with his big brother, but I can have a different — and meaningful — bond with him.

Our relationship has inspired many of the most valuable lessons I have learned in life. To cope with a condition I scarcely understand, I have had to expand my black and white view of the world to make room for gray, for uncertainty and for unpredictability. Together, our son and I have learned to be patient, when it is contrary to our nature to be so. I have developed a level of compassion that I did not have before I was exposed to a world of people who have so many challenges to live with or overcome. I have set new standards for judging his progress and success and, by doing so, I can joyfully celebrate small achievements that were unremarkable for his siblings but are colossal for him.

The U.N.'s proclamation is designed to inspire compassion, inclusion and hope. Hope is an oft-used word these days, described by Webster's as "desire accompanied by expectation." If expectation is at the core of hope, then setting realistic expectations is critical. What can one expect from a person who has a lifelong condition of unknown etiology that affects people in many different ways? What can we expect from the world at large? Understanding of the cause? Effective treatments? A cure? What can we expect from ourselves? Relentless, unending advocacy — at any cost? Recognition of our limitations? A truce with the demon? A peaceful heart?

If life had proceeded as expected, we would be in the throes of the activities that consume families toward the end of high school — sorting through post-high school options, preparing for prom, and undergoing the battles that are part of the painful separation that precedes a departure from the family nest.

Yet that is not our reality. Our son has never attended a high school dance. We have no idea what options will await him when he finishes school next year. He is happiest when he is living at home.

At times my heart hurts when friends talk about their offspring's college applications or my brother mentions my nephew's plan to join the Coast Guard. Fortunately, I find that the peace that comes with acceptance often helps me to hold my nemesis — bitterness — at bay and allows me to be gracious — not jealous — about their achievements.

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