A Different Kind of Different

Category: New Voices
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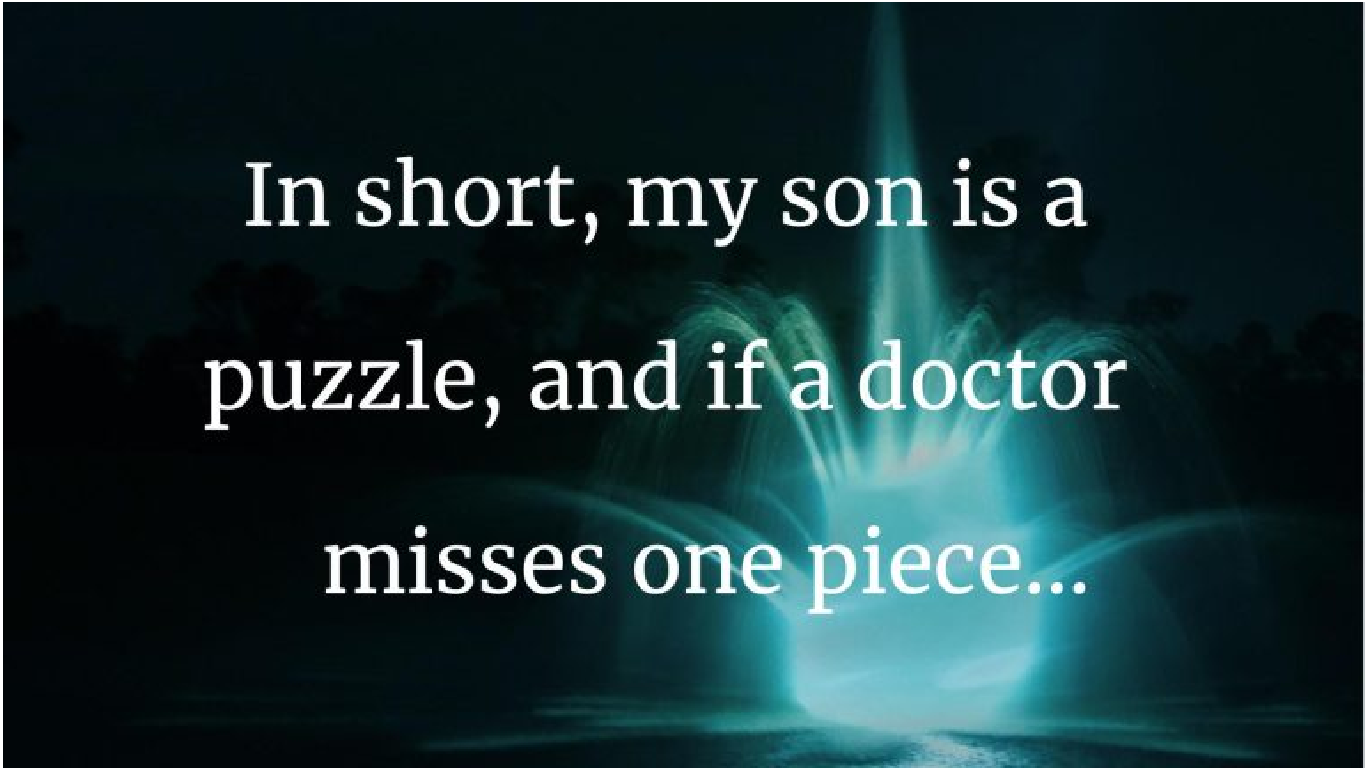

Editor's Note: This piece was a finalist in the Pulse *writing contest, "On Being Different."*

Every parent likes to think their child is one in a million. What if you're the parent of an individual who is more like one in 326 million?

Society in general has started to be more cognizant of disabilities—some disabilities more than others. For instance, Down syndrome awareness and acceptance has excelled in the past several years, and schools have made efforts to teach inclusion and acceptance of students with special needs.

In terms of my own attitudes in this area, I was fortunate to get a bit of a head start. Growing up in the 1960s and 1970s, I was raised not to feel prejudice towards people who are "different." My parents were service-oriented—particularly my father, whose mentally challenged brother had, at age seven, been placed in a mental institution because back then such people were not seen as educable.

Long before it was accepted practice, my father taught me the concepts of inclusion and the normalization of "different." I attended local Special Olympics events; my father sat on the board of Aid to Retarded Citizens (ARC), and after his death a building at the Jacksonville mental-health institution was named for him.

This youthful indoctrination helped to shape my life and career as someone who serves the community and champions people who are "different." (Thanks, Dad!)

In my first marriage, I was blessed with three girls. With my second marriage, my stepson came into our lives. Sam was five, and my daughters, then thirteen, eleven and nine, were well informed about him and became his allies, protectors and advocates.

Sam is “different.” He does not have Down syndrome; he is a “different” different. He was born with a dual genetic anomaly, comprised of Prader-Willi and Klinefelter. Prader-Willi is characterized by short stature, almond-shaped eyes and other traits, most notably an insatiable appetite. Since the appetite has no “shut-off” mechanism, a person with Prader-Willi will forage from the garbage or from other people’s plates, or may sometimes steal food. (Most people know so little about Prader-Willi that they assume your child’s overweight is due to too much junk food. They don’t comprehend that this condition forces parents to turn their home into a kind of jail, with locks on pantries, garbage cans, doors and refrigerators to keep the child from self-harm through overeating.)

With Klinefelter, a male child is born with an extra X chromosome. This can manifest in larger breasts and lack of body and facial hair; it also emerges in open displays of emotion less commonly seen among males—for instance, outbursts of crying in certain situations, or when hormones are heightened.

When we are out in public, people are quick to label Sam (mostly in silence); when we tell them that Sam is a special-needs person, often the response is, “Oh, I have a nephew who is Down syndrome (or autistic),” followed by the implication that we should put him in a group home for people with that disorder. But Sam differs greatly from Down-syndrome children, and from those with only Klinefelter or only Prader-Willi.

Ironically, throughout my son’s twenty-eight years of life, the hardest challenge has not been the staring, the judgmental looks or the whispers or chuckles heard behind our backs; it has been medical care! If we lose or change his established doctors, it’s like being sent back to the starting line right after you’ve finished a marathon.

It doesn’t take a village to care for Sam; it takes a “different” healthcare-system approach, featuring a well-versed primary-care doctor who’s cared for him for at least twenty-five of his twenty-eight years—and oh, man, are we ever blessed with *that* one-in-a-million individual! It also takes a geneticist and an endocrinologist, whom we travel ninety miles to see; some neurologists for possible seizures and memory issues; and an occasional psychiatrist or psychologist.

It also takes a parenting system—in our case, a mom, dad and stepmom who can explain in full detail that he isn’t a “normal” different (deaf, blind, mute, ADHD, Down, etc.). This explanation, in turn, requires additional explanations.

Going to a new doctor involves a two-hour-plus initial appointment. Follow-up visits take an hour at least. Most importantly, this “different” healthcare approach requires a very patient doctor who will listen and not rush out to take care of other, competing obligations. Although most doctors, God love them, direct their questions to our son, they still need the parenting system to interpret his answers. Sam speaks very few words, having been born with tongue-tie—oh, and Prader-Willi also causes low muscle tone, and the tongue is a muscle (see the aforementioned explanations needing explanations).

In short, my son is a puzzle, and if a doctor misses one piece, they'll misdiagnose or fail to adequately address the problem of the moment.

During my almost eighteen years as an administrator at a neuroscience institute, Sam's being a different kind of different spurred me to become a champion for other patients and their families. When I was talking with a patient's family member or scheduling that patient with my institute's doctors, I mentally put myself in the patient or family's position, and I made a point of asking my doctors to do so, too.

Sam's congenital conditions notwithstanding, he doesn't show any sign of seeing himself as different—mostly, I believe, because he is heavily involved in Special Olympics with other young people like himself. I tend to believe that he sees the people who look at him oddly or have trouble understanding him as the ones with the issue.

This seems especially likely to me when I consider that, along with his special needs, he has special strengths. Many one-in-a-million children know how to communicate in, say, two languages—but Sam has been raised to communicate in five ways (talking, signing, drawing, spelling and writing). These skills, to my way of thinking, give him a bit of an edge—especially since he also has a mom, dad or stepmom to interpret.

Perhaps there are many "different" people who, like my son, don't think of themselves as different. Perhaps everyone else should stop viewing them as different as well.

So, dear reader, the next time you see a person who seems different (however you define that), I would ask that you try to gather all of the pieces of the puzzle before reaching any conclusions about them.

And you may also find it worthwhile to spend a few moments trying to understand how *they* may perceive *you.*