



By Caryn Sullivan

WORDS MATTER. JUST ASK A FORMER 'REFRIGERATOR MOTHER'

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In the school of hard knocks, I've learned that words that describe people can have lasting and unintended consequences. In years past, I happily embraced several designations: wife, stepmother, and lawyer. All was well until late 1993, when I was pummeled with a most unwelcome label: "refrigerator mother." This new term attributed my young son's developmental delays (since diagnosed as autism) to my "emotional neglect." The recommended treatment: psychotherapy.

As I continue my journey in this emotionally charged world of autism spectrum disorders (which long ago discarded the fridge mom label) I realize that the words we use have dramatic implications. When a person has such complex medical and behavioral issues, it is perhaps inevitable that we view the person and the disorder as symbiotic. I, like others, have often referred to my son as being autistic. I've also said he has autism. If we say he is autistic are we unconsciously defining the person? If we say he has autism are we describing the condition? Perceptions and expectations seem implicit in the word choice.

Of course my perception of him also influences his perception of himself. Recently, I scolded him for his poor table manners. His response stunned me: "It's my autism, Mom." I wondered whether this was an explanation or an excuse; whether it was his way of defining his confusing world; or whether he was repeating something he had heard from another, quite possibly me.

Is this tendency to label a universal phenomenon? How do people with other medical conditions think of themselves? Is one who gives herself insulin shots a diabetic or someone with diabetes? Is an Iraqi war veteran with a prosthetic leg now an amputee or a soldier without a limb? When I completed my cancer treatment several years ago, I wondered whether I still had cancer, whether I was in remission, or whether I was cured. However, I never thought of myself as "canceristic."

Ultimately, does it matter?

I think it matters, because the issues are broader than how we define the specific medical condition. Years ago, a psychologist explained that my son's autism spectrum disorder (ASD) was a "disability." Aghast, I said, my son is not disabled! He is differently abled. I instinctively shunned the term because it sounded far too hopeless. Although the word is entrenched in our vocabulary, I still have a visceral reaction to it. To me, the prefix "dis" implicitly disses the accomplishments of people who work very hard to navigate an overwhelming world.

The word "challenged" more accurately describes my son. On difficult days, I remind my family that while simple tasks are rote for his contemporaries they are monumental for our guy. To help him compensate for a brain that is not programmed properly, I

become his drill sergeant during the school year. I remind him in explicit detail to brush his teeth, get dressed and hurry so he is not late for school (again). Once he arrives at school, he struggles to successfully traverse a busy, noisy building full of strangers; to hold a pencil and take accurate notes; to deal with the physical requirements and social dynamics of gym class; to get on and off the school bus correctly. Imagining how hard he must work to do things I could do unconsciously, it seems disrespectful to call him disabled. So, I applaud his courage and his effort, even on those distressing days when he takes yet another 15-minute shower without applying soap or shampoo.

I haven't always had this perspective. For years, his constant medical issues and behavioral challenges have consumed me and skewed my view of him. Now that his symptoms are abating, I see a new person. My changing perspective has been influenced by his coach, who calls him an athlete and comments only on his achievements -- a rare experience for us. Being led by this positive perspective, I see his developing abilities and wonder if they were always there, overshadowed by his challenges. I see the young man who holds the door for a woman who carries a cane in one hand and a purse in another, and reports that he did so because he knew her life is hard enough already. Could we have set the bar high enough and helped him to move towards it?

Perhaps these thoughts are simply sentimental musings of one who was castigated as a refrigerator mother. But I cannot accept that this cherished young man is disabled. I think I was right when I insisted he was differently abled. As we parents and professionals work to solve the complex mysteries of ASD, we will be more effective if we respect the semantics. Recognizing the impact the "refrigerator mother" label had on my psyche, I don't want my son or his peers to bear the weight of labels that define them, rather than their condition. By looking at the person rather than the label we can accord all individuals with challenges the respect they earn each difficult day.

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