EDUCATED IGNORANCE

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On my way home from a recent presentation, my flight was delayed at a large airport. Then delayed again. Then delayed again. You know how it goes: everyone in the gate area is miserable, and misery loves company. So over the next few hours, I spent time talking with some of my fellow passengers. One of them was "Abby," who was in her final year of dental school, and was completing her residency.

We chit-chatted about our travels and ourselves, and when Abby learned that my son, Benjamin, has cerebral palsy, she announced, "Oh, we recently had a Special Needs [dental] course and I learned all about CP kids." Uh-oh. In a friendly way, I told her about the importance of using People First Language (and that it was started by people with disabilities), recommending that she say, for example, "children with cerebral palsy," instead of "CP kids." I also explained that the "special needs" descriptor, while commonly used, leads to low expectations, pity, segregation, and other negative consequences.

Prejudice is the child of ignorance.

William Hazlitt

Abby looked somewhat bewildered; she apologized for "offending" me. I assured her that I didn't feel offended, so no need to apologize. I added that I simply wanted to share the perspectives of people with disabilities with her in the hope the info would be helpful. "Yes, it is," she said, "and I'm going to take this information back to school and share it with my professors and other students." I told her that was a great idea, and encouraged her to visit my website.

Somehow, the conversation led to my saying something about "when Benjamin wore braces..." Abby interrupted: "You mean braces *on his teeth?*" "Yes." "You're talking about your son, Benjamin, the one who has *CP?"* I nodded yes, and she exclaimed, *"He had braces <u>on his teeth</u>?"* "Yes..." And it became a slow-motion moment: Abby's eyebrows raised up almost to her hairline, her eyes were popping out and were unblinking, her jaw dropped, her mouth was a perfect O, and she was speechless. I looked at her and said, "What? *What?* Why are you looking at me like that?" She took a breath, shook her head from side-to-side, and said, "I can't believe that. CP kids—I mean kids with CP—*cannot wear braces!"* It was my turn to be stunned and I asked, "Why *couldn't* they wear braces?" "Because," she explained, "they can't *tolerate* them!" I asked, "What does that *mean?* Why couldn't they 'tolerate' them? And who told you this?"

Abby explained that this is what she and her fellow dental students are taught at the university. I laughed and asked what century her professors were living in. I told her that *some* children with cerebral palsy (or any other condition) may not be able to "tolerate" wearing braces, just as there might be some children with *no* disabilities or diagnoses who could also not "tolerate" wearing braces for whatever reason. I shared my opinion that this is the danger in believing you "know" about a person just because you know the person's diagnosis.

Our aircraft finally arrived and we took off. I then spent the next few hours on the flight home mulling over this situation. I thought about how many adults with cerebral palsy I've met who have very crooked and/or missing teeth. It's hard to keep crooked teeth clean, this can result in tooth decay, and that can result in losing one's teeth. I wondered how many parents considered braces for their children, but were told, unequivocally, "No, children with cerebral palsy [or whatever] can't tolerate wearing braces." And no further efforts were made: no parents questioned this nonsense and the orthodontists didn't even try.

I continued musing on the long flight. When my son was an infant and receiving numerous occupational and physical therapy sessions each week, I always stepped in if baby Benj started to cry; I comforted him and told the therapists to do something that wouldn't generate tears. They weren't always happy about this, but they complied. I was saddened, however, by the other very young children receiving therapy in the large room who were often wailing and screaming. I spoke to several of the therapists about this, saying I didn't think children were learning anything from therapy when they were crying and in distress. I couldn't understand how therapists could keep working on a child who was screaming and wailing, making no efforts to comfort the child and/or change what they were doing. Their response? "You don't understand! We know—*we've been taught*—that children with disabilities as young as six-months learn to be manipulative and cry just to get out of therapy!" It seemed they had no common sense and no compassion; they didn't consider that a child might cry because he was in pain, afraid, tired, wet, hungry, or something else.

Next, I recalled an enormous mistake I made before my son entered a general ed first grade class: I gave the teacher a book about "children with cerebral palsy" to read over the summer. I hoped the information would be helpful, and she later reported that it *was* very helpful: she knew that Benjamin would do "such-and-such" and "this-and-that." I told her Benjamin *didn't* do those particular things. Unfortunately, she learned a great deal about CP and *nothing* about my son. I then asked if she could forget everything in the book! (Thankfully, she did, by learning directly from my son and from me.)

Nothing in all the world is more dangerous than sincere ignorance and conscientious stupidity.

Martin Luther King, Jr.

It was a profound lesson: just because a person knows the medical diagnosis assigned to my son and/or the characteristics of the diagnosis, doesn't mean she knows *anything* about Benjamin. The same is true for others. So when a parent, for example, says, "I have a question about my child who has [fill-in-the-blank]," I ask the parent to tell me about her *child,* not the diagnosis. And what about, for example, books about "how to teach children with Down syndrome to read"? *Really?* Are we to believe that all children with Down syndrome learn in the same way?

I've shared a few examples of educated ignorance, and I'm sure you can think of some, too. A person may be highly educated and yet may remain very ignorant. We don't know what we don't know. And because *we think we know,* we don't question.

Going back to Abby, will knowing that my son *could* "tolerate" wearing braces despite having CP make a difference? Will she be able to influence the thinking of her professors? I would hope so, but I doubt it. Do most professors think they can learn anything from their students? When Abby opens her dental office one of these days, will she make adjustments in her thinking and how she practices dentistry? Perhaps; I hope so.

The vast majority of children and adults with disabilities are surrounded by many, many people who exert control and influence over their lives, 24/7/365, cradle-to-the-grave. You might be one of those people: a parent, therapist, service provider, teacher, etc. How many policies, practices, and every-day actions are based on myth, the status quo, conventional wisdom, etc.? Are your actions in the person's life based primarily on what you've been trained to do and/or based on what you think you know about the person's diagnosis? Or are your actions based on what you've learned *from the person?*

Perhaps therein lies the problem. Just as Abby's professors may feel there's little they could learn from their students, many professionals may think there's nothing to be learned from children/adults with disabilities and/or their families, and many parents may feel they would learn little from their children. I don't know who came up with "children with cerebral palsy cannot tolerate wearing braces," but it's not true. Perhaps if just one dental scholar had personal experience in learning from a person with cerebral palsy who *did* wear braces, this myth would be put to rest. (Consider similar situations.)

My son has quashed many myths in his 29 years. We've learned from him; others have, too. Many parents have shared stories when their beliefs (or those of professionals) were changed by reality.

Perhaps therein lies the solution that can eliminate educated ignorance: to be skeptical of conventional wisdom and to learn from children and adults with disabilities. They are the true experts.