

September 21, 2018

She Has YOU to Thank

I want to share some personal observations about how one person with a disability approaches her world. I freely admit that I am working from a sample size of one – my daughter, Cottie. This week, I have been ruminating on the fact that she has a very different idea of her life as a person with a disability than the one that we often see shared in the press, in research, and even on our listservs. And although I think my kid is unique, I don't really believe that she is the only person with a disability who feels this way. Let me share some observations with you.

First – there are a fair number of new folks subscribing to *The Last Word* in the past few months, so I had better start out by “introducing” Cottie to those who haven't heard about her before. Cottie has cerebral palsy. She uses a motorized wheelchair for mobility, and she primarily uses sign language for expressive communication, as her speech is not very intelligible (I have always maintained that all the things she can say clearly are rude, crude, or both). Cottie was adopted from Vietnam 25 years ago, when she was 3 ½ (I am a single parent). She is bright, and beautiful, and loving, healthy, and happy – and (for the moment, I HOPE) she lives at home, with me, and is perfectly happy to let me wait on her. Sigh. My biggest concern has always been that I think the kid is smarter than I am. But because of her Vietnamese heritage, although she is now full grown, I am still bigger than she is. That helps! OK... are you with me so far?

Last week, I heard a presentation given by the founder of a summer camp for people with disabilities here in the Columbus area. They take pwd of all ages (from 7 years old on up). Their model includes one-to-one matching with a volunteer camper who is assigned to partner with the child or adult with a disability throughout their two week stay. They do all the typical summer camp activities, and they accept folks with any kind of disability (from blindness, to CP, to autism, to medically fragile individuals, and more). It is a very successful model. The gentleman giving the presentation spent some time talking about how these camping experiences were life-changing for many of the campers. Never before had they had an opportunity to be in a setting where they were completely accepted, where whatever accommodation they needed was available, and where they had a chance to meet others with disabilities and see them be successful in everyday life. The bottom line is that, for many of these campers, this is the first time their disability is a “neutral” in their lives, and they revel in the experience.

As I listened to the presentation, I kept thinking of Cottie, and thinking about how much she would have been annoyed with me if I had suggested that she attend such a camp. Cottie has never had any desire to attend activities or participate in experiences that are specifically created for people with disabilities. She doesn't see any need to participate in such things. She knows that she is disabled. She just doesn't care, and has never figured out why anyone else does.

When Cottie was in third grade, she dressed up as Nick Carter (of the Backstreet Boys) for Halloween. She wore a short blond wig, the headset microphone from a Via Voice

application, and a Backstreet Boys T-shirt and scarf. The children at her school parade next door through the local Senior Center to show off their costumes. She and I came down from the second floor in the elevator, then waited at the foot of the staircase for the others from her class to come down so she could join them for the parade. As all the Darth Vaders, Spidermen, and Supergirls walked past in their costumes and masks, she was greeted often with, "Hi, Cottie." "Hey, Cottie." "Neat costume, Cottie." My daughter turned to me and, with all sincerity asked, "How do they know it's me?" The fact that she was the only kid in the school district (much less the school) in a wheelchair seemed to have escaped her.

As a 5th grader, she turned to me over dinner one night and signed, "Can I be sick and stay home from school tomorrow?" "No." She went back to eating. I asked her why she wanted to stay home. She laid down her fork and (with great drama) signed, "Oh, because Mr. Long is going to make us run one mile in gym tomorrow, and I just can't face it." (Did I mention she uses a motorized wheelchair? GRIN) Two days later, I was talking to the gym teacher and telling him the story.

"Well THAT explains it. When Cottie finished the one-mile run, she sat on the sidelines and panted with the rest of them. You know I don't cut her much slack. I said, 'Cottie – you were sitting down!' She held up her limp right wrist with her left hand and indicated that her thumb would never be the same."

From the start, Cottie has never seen the need to associate with other kids with disabilities to feel like she belonged, because she ALWAYS believed she belonged. She didn't want to be on the periphery with her classmates, just to say she was there. The year that all the girls in her class joined an afterschool soccer team, I arranged for Cottie to be named the team trainer (picking up towels and packing up supplies) so that she could feel a part of the team, get out there and root for her friends, and be part of the excitement. We went to one practice. ONLY one. At the end of 90 minutes of watching her friends run around on the field, she turned to me and signed, "Why am I here?" But... she joined the Chess Club (and won her fair share of games) and took horseback riding lessons for several years. If she was going to be involved in an activity, she wanted to experience it the same way others did. There were things she couldn't do, but it didn't matter, because there were a lot of things she COULD do.

As I listened to the speaker last week, I tried to figure out why Cottie's view of the world, and her place in it, was so different than the campers he was describing. I came to the conclusion that Cottie has YOU to thank for that – the disability services community. Cottie has been going to AHEAD conferences since she first came home with me (she has been to 22 AHEAD conferences – how many of you can match that?!? GRIN). That means that for one week every year, she spends her time immersed in a setting where people with disabilities are a significant portion of the group. She's seen, interacted with, teased (and been teased by) people who are blind, deaf, in wheelchairs, with service animals – all of whom are mixed in with a whole lot of people who do not have visible disabilities. And everybody there is equal in her mind (and in ours!). She has always had a vision of what the world would hold for her as an

adult, because she has been interacting with adults with and without disabilities all her life. As her mother, I can only say, "thank you!"

[Also this week, AHEAD published the latest edition of their Journal (JPED). There was an article that talked about students with disabilities (in this case, intellectual disabilities) being involved in campus service projects. They interviewed the 6 students with disabilities and the 6 students without disabilities who were partnered with them in the experiment. The six students with disabilities were thrilled with the opportunity to be doing something for someone else. The six students without disabilities spoke primarily about how heartwarming it was to see how happy the experience made their partner with a disability. Bah, humbug. My kid is not someone else's social action project!]

I suppose my point is that while I recognize there are lots of students with disabilities who don't have the experiences and advantages that Cottie has had, I have to believe there are others out there who, like Cottie, don't see their disability as the primary focus of their lives. We give lip service to saying we think that is as it should be, but I think we often think (and treat?) students with disabilities on campus as a separate category, and design opportunities just for them. There was a big discussion on the listserv this week about an upcoming *Disabled And Proud* conference. I know there is an honor society for students with disabilities that has chapters at dozens of campuses across the country. Someone sent me a scholarship notice the other day, for a program specifically for students in wheelchairs. These are all great opportunities for the students who choose to participate, but Cottie would have wanted no part of any of these – and I don't believe she is alone. This is just a reminder that students with disabilities on campus are more LIKE every other student than they are different, and may appreciate that recognition,

Just saying...
Janie

(When Cottie was in 4th grade, she had this poem published in a children's poetry anthology)

*Just because I am in a wheelchair
I don't go out at recess
I don't play soccer
I don't stand up when I say the Pledge of Allegiance*

*Just because I am in a wheelchair
People still think I'm funny
People still think I'm a good kid
People still treat me like everyone else*

*Just because I am in a wheelchair
I can still do fun things
I can still beat you at chess
I can still make you laugh*

Just because I am in a wheelchair doesn't mean I'm not a regular kid