

Memories

Testimonies About the Living, Not Just the Dead

Revolutionary Common Sense by Kathie Snow, www.disabilityisnatural.com

With tears streaming down her face, the mother of a teenaged girl who was killed in a car accident described her daughter to the TV reporter, “Everyone loved her—Suzanne was kind and sweet, she volunteered at the Senior Center, and she made friends with everyone she met . . .” We see or read similar descriptions in the news, as well as in the daily obituary column. And what do all these reports—these memories—have in common? *They are always positive!*

During the television interview, Suzanne’s mother did not reveal that her daughter made a “D” in math, kept a messy bedroom, had two speeding tickets in the last year, was disrespectful to her father, or any other not-so-positive characteristics. Why? Why do memories of the departed seem to always focus on the positive and not the negative? Because that’s the way *we* want to remember our loved one, that’s the image we want *others* to have of her, and because those were *the most important characteristics* of the person—*what we valued the most*.

Positive memories are helpful to the living, not the dead. We, the living, focus on the positive—in obituaries and when talking about the dearly departed at wakes and services—to help permanently etch this image in our minds. Days, months, or years later, this image typically overpowers any not-so-flattering or negative remembrances.

What if we applied this practice to the *present*—today, here and now—to the individuals with disabilities in our lives? How might that change the way *we* see them? How *others* see them? *How they see themselves?*

First, try this little exercise: think about what you want written in your own obituary. It will all be good, right? It will include some of your accomplishments and interests. Now think about writing the obituary for the person with a disability in your life—your child, a student, or a person for whom you provide services. Make a list of the positive characteristics you want others to know about the person. If you need a little help with this, review the obituaries in your newspaper. I guarantee that all the people you read about had medical diagnoses of one kind or another, there were many things they couldn’t

do, and they generally led “imperfect” lives. But you’ll find none of that in their obituaries.

So write a list of things to include in an obituary for the person with a disability in your life. Then compare the list with how *you* typically see the person, how *others* see her, and *how she sees herself*. Are they all similar or is there a huge disconnect? Is it possible the person you’ve described on paper seems like a different person than the one who lives and breathes in front of your eyes? If so, it’s time to make some changes!

When I do a presentation on attitudes, perceptions, and People First Language, I usually begin by telling something about myself and my family, to help the audience know me a little better. I share that “attitude is everything,” and illustrate this by talking about what my son has done, what he’s interested in, and so forth. The point being that, even though Benjamin uses a power wheelchair and has many needs (don’t we all?), my husband and I have adopted the attitude—and the actions to support the attitude—that Benjamin’s disability will not get in the way of who he is, what he wants to do in life, or anything else. And now I’ll share a couple of these stories with you.

When Benjamin was about 13, he decided he wanted to be an actor—and not just any actor, but the first James Bond who uses a power wheelchair! He wanted machine guns, an ejector seat, rocket-propelled grenades, and other goodies on his chair—just like Bond’s car. Benj has the skills needed to be an actor: he has a great auditory memory, can do accents, and is a big ham! So we enrolled him in drama classes, and over the next couple of years, he performed in several children’s theater productions.

Then when he was almost 16, he made a big announcement at the dinner table. Before going further, let me add that in our house, the rule has always been, “Whoever is closest to Benj helps him.” So even when our two kids were very young, big sister Emily learned to help Benj with his coat and other things. (And Benj has to help others, too. People with disabilities cannot always be recipients of help—this feels awful. They must also be givers of help.) So Emily often helped Benj learn things that she learned to do first.

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Now back to the dinner table and Benjamin's big announcement. With great fanfare, he proclaimed, "Pretty soon I'm going to turn 16 and I'm really excited about that, 'cause when you're 16 you can date, and when you date, you get to kiss. *And*, when I'm James Bond, I'll also need to kiss. So, Emily, I want *you* to teach me how to kiss!" Emily's eyes opened wide, her face turned white, her mouth hung open, she almost threw up, and she finally gasped, "Mom! You're not going to make me help him with *this* are you?"

I agreed that this was not in her realm of responsibility, and Benjamin furiously yelled, "Why doesn't she have to help me? Who's gonna' help me learn to kiss?" I replied that he would have to learn to kiss like everyone else—by kissing the mirror, the back of his hand, or his pillow—but *he would not be kissing his sister!*

So I sometimes tell these, or other stories, during the beginning of the presentation. In the next hour or two, I focus on the problems caused by old language, negative labels, and stereotypical attitudes, and I conclude with recommendations on how to change and improve things. One of these includes the importance of focusing on a person's strengths, gifts, interests, and abilities. When I wrap up, I sometimes ask the audience how they'll remember my son. The answers almost always include: "He's been an actor," "He wanted to be James Bond," "He has a great memory," "He wanted to kiss his sister," and/or other interesting and positive images.

Seldom does anyone mention anything about his diagnosis, his wheelchair, or anything related to disability. And that's the point I'm trying to make: *how I present my son to others will determine how they see him*. And when anyone meets him in person, how *he presents himself* will influence how others remember him. Sadly, I have met adults who have learned—by imitating others—to talk about their diagnoses when they meet someone new!

Most importantly, I share that *every* child and adult with a disability needs to be known *not* by their diagnoses or what they cannot do, *but by what they love to do, what they're good at, what they're interested in, and more!* At that moment, many parents in the meeting room feel a heavy

heart, knowing that, in general, they have *not* presented their children in the most positive (and accurate) light. They have, instead, presented them by their diagnoses and/or so-called problems and deficits, a habit they've *learned* from professionals in the health care, educational, and/or service provider industries. (But we can replace bad habits with good!)

For far too long, we have hurt and humiliated individuals with disabilities by focusing on their diagnoses and a wide variety of negative descriptors. We have set them up for failure by sharing these negative images with others. We have seen them as unable, incompetent, and more, because we haven't been able to see past these negative images. And, perhaps worse, we have caused them to see *themselves* in the most negative ways. How insensitive can we be?

With the dearly departed, as previously mentioned, focusing on positive memories effectively erases the negative memories. But with children and adults with disabilities, *who are alive and with us today*, some of us cannot even *see* the positives, for we've allowed the negative images to become the defining characteristics!

If our hearts and minds are big enough and strong enough to remember what was wonderful about someone who is now dead, *can we not do the same for someone who is living?* Can't we focus on their strengths, their abilities, their gifts and talents, the way they make us laugh, the kindness they show others, the hopes they have for the future, and so much more?

Can't we spend more time valuing and building on the positive instead of trying to change what we've perceived as negative? Won't we then realize what's really important, and help others do the same? Most importantly, will our "new and improved" perception of the person *change the way he sees himself?* Many of us may know people with disabilities who have very low opinions of themselves, *based on how they have been treated or talked about by others*. The consequences of our insensitive actions can be harmful and long-lasting. We can change this, by widening our vision, seeing the positives, and sharing the good news with others, including—and especially—the person who has been labeled with a disability diagnosis. Attitude *is* everything.

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