

March 16, 2018

You Can't Please All of the People, All of the Time!

In April, 2014, I wrote a post entitled "Damned If You Do..." Here is an excerpt:

This week, I have had several reminders of a topic that I once wrote about in my newsletter. I believe the article back then was called "Damned If They Do, Damned If They Don't." I've looked everywhere, but I can't seem to find a copy of that older article on my system, so I'm going to have to try to recreate the important pieces here.

That earlier discussion arose from a great deal of furor on the listserv regarding the issuance of the Alabama State Quarter, with its likeness of Helen Keller and the motto "Spirit of Courage." The coin also has Keller's name in Braille, albeit very tiny Braille! Some folks on the listserv were thrilled that Helen Keller, a person with a disability, was chosen to represent the state, and that her achievements were to be commemorated with this coin. What a great way to celebrate disability as a part of the fabric of America! Others were angry. Some felt that the "honor" was no honor at all – just the nondisabled community patronizing people with disabilities once again. (That group was particularly unhappy with the "Spirit of Courage" designation. "Overcoming disability through courage" is a nondisabled conceit, not something we promote in the disability community.) Others objected to Helen Keller as a representative of the disability community, citing her less-than-typical experience for a disabled person in her era (because of her wealthy family background), arguing that there were other deaf-blind individuals before her that had been successful, and throwing out furtive speculation about her worthiness for recognition because of her reported flirtation with socialist politics. Another group found it offensive for the State of Alabama to have chosen Helen Keller as their representative when the State has a lousy track record for service/support to people with disabilities.

As I read through the rather heated discussion on the listserv, I was speculating on how professionals in the same field could have such different reactions, and wondering whether folks from outside disability services would even understand the argument. It reminded me of a personal incident when I was struck by that same question.

Many years ago I went to see the stage production of Children of a Lesser God in Chicago. The lead role was being played by Linda Bove (the woman who played the deaf character on Sesame Street for many years). During the intermission, I got into a casual conversation with the nice lady (stranger) sitting next to me. I told her that I had seen the production in New York with the original cast, including Marlee Maitlin. She said, "I'll bet it was even more powerful when the lead was being played by someone who is deaf." I was a little bewildered and said, "But Linda Bove – the actress here – IS deaf." She said, "Oh, no. I don't think so. I was just looking at the Cast Notes description of her background and it doesn't say anything about her being deaf." I had read the Cast Notes myself and been impressed with the fact that they DIDN'T mention

Bove's deafness. I remember thinking, "Good! They are talking about her acting achievements and her deafness isn't a part of that one way or another. That's a really positive step forward in terms of how disability is presented and perceived by the general public."

I said, "But those notes are a description of her acting credentials. Why would it say anything about her being deaf?" And her response was, "Well I think people would want to know that!" My first thought was annoyance – would this woman think that her performance was better because Bove was deaf and therefore wasn't expected to be doing so well? How demeaning. The lesson to be learned was that you DIDN'T know Bove was deaf unless you were told, and wasn't that a great way to make a point about the capabilities of people with disabilities. And then I realized that if we didn't TELL the public that she was deaf, they wouldn't know, and then they wouldn't learn anything!

That is when it hit me that the nondisability community is "damned if they do, and damned if they don't!" We accuse them of being patronizing when they celebrate the achievements of people with disabilities ("what does being disabled have to do with it?") and we accuse them of being stupid when they DON'T recognize the achievements of people with disabilities!

Of course, the discussion about the Alabama quarter was kind of the reverse of a discussion, several years earlier, about the FDR memorial. In THAT discussion, the disability community fought to have FDR's disability publicly recognized, while others fought to minimize the impact of the disability on FDR as a person and as a President. Damned if they do, damned if they don't!

We lost Stephen Hawking this week.

It struck me, in preparing this piece, that Stephen Hawking may be the perfect "in between" example between FDR and Helen Keller. His fame had nothing to do with his disability (while Helen Keller was famous BECAUSE of her disability). But his disability was well-known and the public image of him was ALWAYS as a man in a wheelchair with a significant disability (as opposed to FDR, who felt it necessary to hide his disability – a different time, a different world). And, yet, while you could say that Stephen Hawking represented only the most positive issues/lessons learned from FDR and from Helen Keller, responses to his death have thrown us back to EXACTLY the same argument we've been having for years.

Stephen Hawking was a hard person NOT to like. His achievements in math, physics, and cosmology were legendary. There is no doubt that he will be remembered, just as Einstein is remembered, as someone who forever changed our understanding of the world around us. How could you not respect someone like that for what he has done? Moreover, he did it all with a sense of humor and a streak of fun (with guest performances on *Star Trek: The Next Generation*, the *Big Bang Theory*, and *The Simpsons!*). He didn't deny that he was brilliant, but he didn't think that was the most

important thing in life, either. It appears he was a generally good guy. Did he have flaws? Sure. The fact that he wasn't perfect doesn't mean he wasn't a truly unique individual, worthy of admiration.

Stephen Hawking readily acknowledged his disability (it would have been hard to ignore), but didn't see it as either a positive or a negative in his life's work.

"My advice to other disabled people would be, concentrate on things your disability doesn't prevent you doing well, and don't regret the things it interferes with. Don't be disabled in spirit, as well as physically."

But how did the rest of the world see Stephen Hawking and his disability? In preparing this piece, I checked out some articles in prominent places:

<https://www.aol.com/article/finance/2018/03/14/physicist-stephen-hawkings-net-worth-legacy/23385898/>

<https://www.nytimes.com/2018/03/14/obituaries/stephen-hawking-dead.html>

<https://www.wsj.com/articles/stephen-hawking-who-bridged-science-and-popular-culture-dies-at-age-76-1521000561>

There are a couple references (in the Wall Street Journal entry) to Hawking being "wheelchair bound," but, for the most part, the articles seem focused on his accomplishments, acknowledging his disability but not seeing it as the most important thing to remember him by. I was pretty impressed. And then someone sent me this link:

<https://usat.ly/2GrG8R8>

Obviously, the people who were quoted in this article were reading a lot of different tributes to Hawking than I was. I thought the reference to "inspiration porn" was catchy (used in the context of honoring Hawking because he was an inspiration to people because of his disability). But I am not sure whether the general public's response to the passing of Stephen Hawking was really so inappropriate, or whether these folks saw what they expected to see. Even if they DID see a lot of inappropriate references or phraseology, which is a better use of time, energy, and bandwidth – to bemoan the stupidity of people who don't understand the reality of living with a disability, or to remind folks (while they are in the mindset to listen!) that Stephen Hawking was a remarkable man AND that Stephen Hawking had a disability (not because of, not in spite of, but ALSO)?

Is the disability community missing out on a great opportunity to celebrate one of our own because we are so focused on what other people MIGHT think about his disability? What a waste.

I have attached a cartoon image someone shared with me the other day. My apologies to anyone who finds it inappropriate or offensive. I found it wonderfully irreverent.

Janie

Quotes from Stephen Hawking:

On free will

"I have noticed that even people who claim everything is predetermined, and that we can do nothing to change it, look before they cross the road."

On the Eureka moment of a new discovery

"I wouldn't compare it to sex, but it lasts longer."

On what he thinks about all day

"Women. They are a complete mystery."

