

January 29, 2021

A Rose, By Any Other Name...

Recently, AHEAD issued a communiqué to members, letting them know that the Association has chosen to take a deliberate and public step in promoting consistent use of language in all AHEAD publications. Specifically, the Association is consciously moving to the use of identity-first usage:

There are two prevalent ways that we identify with disability in language: person-first and identity-first. Both options have implications for how we think about disability.

Person-first language distances the person from the disability, ostensibly to separate the person from the negative connotations and stigma with which we have all been socialized. As professionals, many of us have been taught that person-first language is preferable, and some disabled individuals choose to identify as a person first, based on their personal orientation to disability. Example: I am a woman with a disability. I am separate from the stereotypes and stigma you associate with disability.

Identity-first language challenges negative connotations by claiming disability directly. Identity-first language references the variety that exists in how our bodies and brains work with a myriad of conditions that exist, and the role of inaccessible or oppressive systems, structures, or environments in making someone disabled. Example: I am disabled, queer, and Latinx. I have an impairment, and I am disabled by societal barriers.

(snip)

As AHEAD moves to promote concepts of disability informed by social justice, we are adopting identity-first language across all communication, information and materials. This is not a directive or a recommendation about how others should identify; it is one way to model new thinking on disability that we see reflected in disability studies and in the disability rights community.

(NOTE: AHEAD is holding an open forum for members to discuss this communiqué and the importance of the issue this afternoon, January 29. See <https://www.ahead.org/professional-resources/accommodations/statement-on-language> for more information.)

I don't have a problem with the idea of taking conscious aim at changing the way we talk about people and processes within our field. This particular format/usage may be different, but the understanding of the impact of language on perception is not. The way we talk about people makes a difference in the way we think about people. One of the most impactful disability awareness posters I have ever seen came out in the early 80's, and it showed two pictures of a gentleman in an old-fashioned wheelchair, with a high wicker back and very narrow tires (like those used on a bicycle). In the first picture, the

gentleman had his back to the viewer and the caption read, “People who didn’t know this man called him a cripple.” In the second picture, he was facing the viewer – it was FDR. The caption read, “People who knew him called him “Mr. President.”

Moreover, the folks at AHEAD recognize that their choice of language may not be comfortable for everyone, and they are fine with that, too (“*This is not a directive or a recommendation about how others should identify...*”). You hear the word “transparency” thrown out a lot these days, as something lacking from too many public entities. I appreciate the fact that the AHEAD Board is making a conscious effort to be open, transparent, and approachable.

I admit that I am a product of that earlier age – the ones who were taught that people-first language was preferable. And I remember WHY we considered it preferable. I am old enough to remember the original legislation that established special education programs in this country – Public Law 94:142. It was originally know as the EHA – Education of the Handicapped Act. In the early days of our profession, the HEATH Resource Center was an incredibly valuable resource for students interested in pursuing higher education (HEATH was the consumer arm that matched our fledgling professional organization). HEATH stood for Higher Education And The Handicapped. When we moved away from the use of the word “handicapped” and moved to “disability,” we also moved toward the use of people-first language. That is why, in the early 90’s, the federal government gave us the Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act (ADA) – both prominently featuring people-first language. But that was then. This is now.

I am not opposed to changing the language we use, but I got to wondering why it seemed so important to the AHEAD leadership that they chose this very formal statement of intent. Then I read an article called *Student Protests, Past and Present* (<https://tinyurl.com/IHE-StudentProtests>). It talks about placing today’s student protests into historical perspective. This is the paragraph that jumped out at me:

*What have scholars learned about student protest movements? * That student protest is cyclical and generational, surfacing, surging, retreating and resurfacing, and that the generational component is crucial, inspiring and informing the tactics and rhetoric of new generations of activists.*

Perhaps that is what we are seeing in AHEAD’s very public embrace of these stylistic communication changes – the rhetoric of a new generation of activists in pursuit of an old goal. Our shared goal is to promote a more inclusive world of higher education where students with disabilities can thrive. Oh. Wait. That should be “where disabled students can thrive,” right? Old habits die hard. GRIN

If this is how the current leadership feels that goal is best served in society today, I’m ready to get on board, although my guess is that it will take me a while to get the hang of it. I wonder, though, if while we are revamping the terminology used to describe our students, we will also revamp the terminology we use to describe ourselves and what

we do.

Every few months, the same conversation surfaces on our professional listservs. What should the name be of the office that provides support and services for disabled students? And each and every time, there are philosophical arguments trotted out for why to include or not include the word “disability,” why to include or not include the word “access,” how to describe what the office does without stigmatizing the students it serves, ad infinitum. The last reported survey of the AHEAD membership (2018) showed that only 58% of the office titles represented in that survey included the word “disability.” Do we get to reclaim it now? Do we go back to talking about “disabled student services” instead of avoiding reference to who we serve with the less direct reference to “disability resources?” How far will “identity-first” language take us?

What is your office currently titled? What will it be called six months from now? Just asking! GRIN

Janie

I dislike the word “manipulator.” I think of myself as an “outcome engineer.”

He isn't mad. He is just...differently moraled.

You are not allowed to call me a dinosaur anymore. It's speciesist. You should refer to me as a pre-petroleum person.

February 5, 2021

What's in A Name?

Last week's offering was titled “A Rose By Any Other Name...” and spoke to the public announcement, by AHEAD, of their intent to adopt identity-first language in discussing disability in their publications.

I admit that, in writing that piece, I was thinking along the lines of the benevolent old-timer, sitting around the table at a family Thanksgiving gathering, listening to the youngsters' impassioned explanations of the issues of great import to them in society. Mostly, those old-timers sit back and listen indulgently, thinking “I wish I had that kind of energy these days!” I had no problems with the adoption of identity-first language, I just didn't (and don't) see it as being nearly as meaningful a change as, apparently, others do.

In the intervening week, I have been rethinking my blasé attitude about all this, in light of comments from readers and the recognition of some buried assumptions in the justification of AHEAD's change that could be interpreted in a different way.

I had a number of responses from folks after my post last week – a surprise to me, as I

often get no responses at all. (The *Last Word* posts aren't written with the idea of eliciting response, although I am always glad to discuss the posts further with folks.) One post was from a graduate student in disability studies who thought AHEAD's new approach was the best thing to come along since sliced bread. The other responses were uniformly... less enthusiastic. For instance:

I, as well, am from the era of "old school" thinking. I do question though if the activists you speak of understand the pulse of the majority of students with disabilities or if it is just to be progressive. In my midwestern world we still have a ways to go with decreasing disability stigma and this language change does not feel helpful to that end. I spend much time with students who sometimes have a hard time just walking through the door.... assuring and encouraging them that having depression or anxiety is just a part of the package and not ALL of who they are.

and

How does society generally catch up to changing language? How easy will it be to recondition society to use of proper address when the address keeps changing? ... In a world that has yet to catch up, does it make sense to play this continuous game of label tag? While as a disabled person there is dignity in disability does society at large understand that or does society still perceive disabled persons as dependents and incapable?

and

...The names seem to mean more to the professionals than the people who are looking to use the services.

Then I went back to look up the original quote, and it seems that my subject title was a popular – but truncated – rendition of the quote from Shakespeare's *Romeo and Juliet*. In Act 2, Scene 2, Juliet says, "What's in a name? That which we call a rose, by any other name would smell as sweet." Juliet was saying that what something or someone is called is not as important as what or who they are.

Interestingly, though, as I was researching this, I ran across a website that offered "Roses with Names," referring to a selection of cut roses sold under a "name" to make certain that a client's next purchase will be the same in terms of smell and color. Apparently, a rose by any other name may NOT smell as sweet (as the one originally purchased)!!!

That brought me back to the discussion of language use. Is it really all the same or do different ways of describing the experience of disability carry different implications? Here was another response from last week:

Prior to my retirement there was a move afoot to change language on campus. It was coming from the younger population of students and staff, part of a newer crowd. Not

disrespecting their right to choose the language they do I made it clear my reasons for keeping language as people first. Disagreement but no argument. ... That said, it seemed to be coming more so from persons with invisible disabilities who appeared, with all due respect to them, not to be affected in everyday life in any substantive way.

In some respect it seemed almost in the same way that we had to fight for the rights of people with disabilities 40 years ago or more for equal respect and treatment including language. Now that we have legislation what do young people have to fight for? Maybe it is the right to own their language as a means of supporting the narrative.

That is an interesting thought. Are people with invisible disabilities, who have been less likely to experience stigma and discrimination because of their disability, more likely to gravitate to identity-first language, while those with visible disabilities who HAVE experienced consequences from society as a result of their obvious disability more likely to want to maintain people-first rhetoric?

In the position statement regarding the shift in language, AHEAD said:

Person-first language distances the person from the disability, ostensibly to separate the person from the negative connotations and stigma with which we have all been socialized.

Maybe. Maybe that is why some prefer people-first language – to get away from the negative connotations and stigma. But maybe people-first language serves a POSITIVE purpose. Maybe it serves as a reminder that *people with disabilities* are part of a larger population – “people” -- and BEING part of that population makes them more like everyone else than it makes them different, and empowers them to fight for the same things everyone else is fighting for. For example...

... the DREAM Student Organization (Disability Rights, Education, Activism, and Mentoring) is hosting a Town Hall meeting to discuss important topics identified by their chapter affiliates:

- * Racial Justice
- * Campus Accessibility
- * Self-Advocacy
- * Assistive Technology
- * Receiving disability accommodations
- * Health care
- * COVID

I am guessing they will be discussing those issues in the context of being disabled students on campus. The first and last – racial justice and COVID – are issues being discussed by all students on campus these days, while the others on the list are likely limited in interest to students with disabilities. What struck me, in looking at the list, was not what was there, but what was missing.

I have been reading a lot lately about problems of equity that existed on campuses across the country before the pandemic that have been worsened by our current situation. Hunger on campus has been a growing concern for several years. All indications are that it has worsened in the last year. Students who were dependent on part-time jobs in the food service industry or retail have seen those jobs disappear as the lockdowns have impacted jobs and the economy in general. Closed campuses may also mean closed food pantries. Students with children now being home schooled may find that not only their time but their resources are additionally stretched by the loss of support from other entities.

Then, too, as I was writing this post, I received an email about a new report from *Inside Higher Ed* called, "Bridging the Digital Divide."

The report, by Lindsay McKenzie, Inside Higher Ed's technology reporter, explores how certain groups of students were affected by limited access to technology and Wi-Fi networks as colleges pivoted to remote learning because of COVID-19. Discover the breadth of social and economic disparity among students that this transition exposed, along with strategies undertaken by institutions, faculty members and others to help students who already faced great barriers to completing an academic program.

I don't see either of those issues showing up on the list of things that DREAM will focus on in their upcoming Town Hall. THAT is my concern. In the process of celebrating their disability identity, are these students isolating themselves from the issues of students, in general? In celebrating the "us" will they be ignoring the "we"???

As my correspondent said, "disagreement but not argument." There are certainly points to be made on both sides, and room for everyone to choose the use of language that most comfortably fits with their philosophy and current headspace. I just thought it important to remind folks that the choice of language may not be as benign as I thought – there ARE consequences, either way.

Stay safe. Stay well.

Janie

Names don't matter. Meanings do.

I stopped explaining myself when I realized that people only understand from their own level of perception.

Your elevation may require your isolation.