The Importance of Using Our Words Wisely (The Language We Use: Part 2)

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In my recent column, I talked about language, and how important it is that we use words carefully because they can convey attitudes, and values. We can use language that, even if it's not our intention, can offend someone, or make them feel "less than" and adds to misunderstanding or increases stigma. Or we can use language that helps lift people up and that helps build bridges.

I used two examples in that column: preferred language to refer to people living with HIV, and also language that helps people understand the difference between the terms HIV and AIDS. Preferred choice of language changes with time, and HIV-related terms have changed substantially as the disease has changed over the past three decades.

When TIHAN was founded in 1994, we put the word compassionate in our tagline. Since then, other organizations have changed their taglines to include "compassionate" too. Likewise, we call our direct service programs "care and support services" instead of "client services," and that change also has been adopted by others.

Does it matter if you are a person living with HIV if someone calls you a client, or a patient? Regardless of what someone calls you, you're still the same person. But it might affect how you feel about yourself and your role, and it might also give others some clues about how they should view you.

At TIHAN, we try to avoid the use of words like client and patient, which seem much more medical. Our goal of reducing HIV stigma leads us to want to use words that, instead of causing separation, make people realize that we are more than a medical case, and that we all have more in common than those things that might separate us.

Still, in our culture we need to use words to describe and differentiate. So even though we'd prefer not to separate into "us" and "them," we do need words to help explain things. So long ago we had discussions about what words to use to refer to persons living with HIV that wouldn't be medical (since we don't provide medical care). Some organizations use the term "consumer" which we didn't choose because it sounded so business-like.

Other organizations prefer to say "care receiver" or "care recipient." We chose not to use those terms because they make it sound so one-sided, as if a person living with HIV is only able to receive from an HIV service organization like TIHAN. We know better than that—our volunteers so often talk about receiving as much, or more, than they give, and really benefit from the mutuality of the relationship. So we chose a term that we felt fit best, although it's awkward and easily confused! We chose the term "Care Partner" for someone living with HIV who is connected with TIHAN, to signify that we believe that people should always be partners in their own care and be active participants in their support services, whether those are medical, behavioral, or social.

So if you see or hear someone talking about being a Care Partner, or working with a Care Partner, now you know what that means! Sometimes, when people are becoming involved with TIHAN, they have to adjust to our language, because they're often very new at working and volunteering in the HIV field.

A few of the common terms that people have to get accustomed to changing are really basic to some of us who've been around for a while.

Some people still use the word handicapped, and we encourage them to use the terms "people with disabilities" or "differently-abled." We encourage people to not use the term homosexuals, but instead use the word "gay" or, depending on the situation, "men who have sex with men."

There's a whole long litany of different terms for people with various gender and sexual orientations, but one of those that seems to be most misunderstood is "bisexual." So many people think of a bisexual person as someone who has sex with men and women, but I prefer to think of a bisexual as someone who is sexually or romantically attracted to the person, regardless of their gender.

Likewise, "drug user" isn't preferred language anymore, but instead it's now people who use substances. We no longer talk of "high risk populations" now, but instead remind people that it's "higher risk behavior" that's most important. Because we know it's not who you are, it's what you do, that might put you at greater risk for getting HIV. The human immunodeficiency virus doesn't know—or care—which population you are part of: it's just a virus that is transmitted in certain specific defined ways (behavior).

A term that's been used since HIV was first identified is "universal precautions," the medical concept of assuming that anyone's blood or body fluids might be carrying HIV (or hepatitis or other blood-borne pathogens) so you take precautions like wearing gloves to avoid the risk of coming in contact with the virus, and you do it universally—with everyone. That term universal precautions has been changed to "standard precautions," helping to better remind us that it's standard behavior to take precautions, and not to be done only when you think someone's blood may contain HIV.

So those are some of my thoughts about language. It's a fascinating and ever-evolving world we live in, and while we might sometimes use old language that is no longer preferred, but as long as we're doing our best and not being malicious, no one will take offense, knowing that we're all learning as we go and becoming more understanding and sensitive to those around us, helping us all to feel "a part of" rather than "apart from."

If you are interested in getting more involved in TIHAN and helping address the stigma of HIV and also helping support persons living with HIV, please call TIHAN at 520-299-6647.