The Language We Use: Part 1

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By Scott Blades, Executive Director
Tucson Interfaith HIV/AIDS Network (TIHAN)

I've been thinking a lot lately about language, and how important it is to consider carefully the words we use. I know sometimes I need to take more care in using language that is as clear and sensitive as possible.

I recently read an article about the importance of using "people first" language. Author Carey Goldberg was referring to a headline in The New York Times that used the term "the mentally ill." She called out the paper for using that objectionable language with the word "the," as if all of "the mentally ill" can be put into one category, separate and different from (less than?) the rest of us.

> "I try a thought experiment, the headline 'Equal coverage for *the* women.' Weird. 'New era for *the* gays.' Offensive. 'Crime and *the* blacks.' I get the point."

"People first" language means that we use language that refers to people first and foremost as **people**. A person is a person first before anything else that may describe a part of them. People with disabilities instead of disabled people. People living with HIV instead of HIV people.

Also, recently there was article in our local newspaper mentioning that TIHAN helps those "afflicted with HIV." At TIHAN, we never use that word "afflicted" and I cringe when I hear others use it, because it's a word that adds to the stigma and sense of victimization. It's not only a word seen as insensitive--it's actually perceived as offensive to many people.

These two occurrences reminded me of an article I wrote when TIHAN first started almost 20 years ago, parts of which are below, in italics. The article was about language that was new and groundbreaking 20 years ago, but it's pretty basic today, at least in the community of people living with and working with HIV.

> *The language that we use to describe one another is very important. As we know, words can convey attitudes, values, judgment, and separation. As different peoples have worked to end discrimination and secure their rights in this country, the terminology used to refer to them has changed and evolved over time. Here are some suggestions regarding appropriate language.*
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> *We do not use the terms "AIDS victims," "AIDS persons," "AIDS people," "AIDS patients" for several reasons. "Victim" implies defeat and passivity. People living with HIV and actively fighting AIDS are not passive victims. "Patient" implies that the subject is receiving medical treatment, when in fact people living with HIV are often either undiagnosed or untreated (due to a lack of medical insurance, for instance). Also, patient implies a distinct separation and diminution. "AIDS persons" overtly defines someone based solely upon their medical status. HIV status is just one component of who we are.*

I love this comment from the UNAIDS Terminology Guidelines (revised in October 2011), "'AIDS patient' should only be used in a medical context (most of the time a person with AIDS is not in the role of patient); the term 'AIDS victim' or 'AIDS sufferer' implies that the individual in question is powerless, with no control over his or her life."

Referring to someone as "HIV-infected" is also offensive to many people because it focuses on someone being "infected" and adds to the stigma that is still too often attached to this disease. HIV is a virus that is transmitted in certain limited ways, and should not have any stigma attached to it. It's a medical issue, not a moral issue.

> *The phrase "innocent victim" is particularly offensive and should always be avoided as it implies that some people living with HIV are "guilty." Accusations of guilt, which typically are directed at those who contracted HIV through sexual contact or substance abuse, compound the discrimination that burdens people living with HIV and hampers efforts to educate the public about AIDS. The distinction between innocent and guilty people is artificial and destructive and is not our judgment to make."*

Another important piece of language that is often used misunderstood is the use of the words "HIV" and "AIDS," and the difference between the two.

HIV stands for human immunodeficiency virus. HIV is the virus. AIDS stands for acquired immune deficiency syndrome. AIDS is a medical condition that happens to some people after they have been infected with HIV and the virus has weakened the immune system over time. Terms like "AIDS virus" or "AIDS test" just aren't accurate.

HIV disease can be viewed as a spectrum, ranging from initial infection to end-stage disease when the immune system is significantly compromised (diagnosis as having AIDS). Someone with HIV can be said to have HIV disease (or HIV-related disease), but may or may not eventually have advanced HIV infection that leads to an AIDS diagnosis.

For someone living with HIV, referring to them as having AIDS may or may not be correct, and might be hurtful to say.

What is considered sensitive, respectful, and less offensive language changes over time as our world changes. In the last 30 years, AIDS has gone from being a short-term and usually terminal condition to how it is considered today: a possibly long-term and chronic manageable condition that, when treated, might not limit lifespan at all.

Hopefully someday soon we will have a vaccine to prevent HIV infection, and a cure for those who are living with HIV. Until that day comes, let's work to be more educated and sensitive in our choice of language we use. I'm sure going to try to do better with this in this new year.