WISCONSIN AIDS/HIV PROGRAM NOTES

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Using Person-Centered Language to Address HIV-Related Stigma

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HIV prevention and care efforts are negatively impacted by stigma.[1,2] When people living with HIV are faced with negative beliefs, feelings, or attitudes at healthcare facilities, they may be less likely to seek medical care.[1] When people in need of HIV prevention services face a similar environment, they may opt to forgo testing, which hinders HIV prevention efforts. While stigma must be addressed from many levels, one action taken by the AIDS/HIV Program has been to increase organizational awareness of its use of language. Through our reports, publications, and presentations, the AIDS/HIV Program is committed to signaling to partner organizations, health care providers, and people living with HIV the importance of using language that does not—intentionally or unintentionally—contribute to stigma. This issue of *Wisconsin AIDS/HIV Program Notes* highlights ways in which the Wisconsin AIDS/HIV Program is implementing the use of language that is compassionate,[3] accurate, trauma-informed,[4] and responsive to the unique needs of individuals and communities affected by the HIV epidemic.

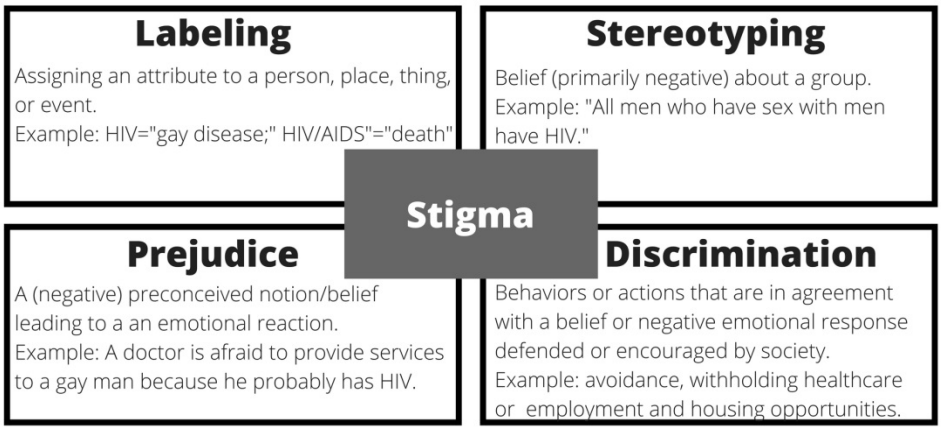
Figure 1 presents a model breaking stigma down into four elements:

- Labeling
- Stereotyping
- Prejudice
- Discrimination

In brief, *labeling* is the act of assigning an attribute to someone. *Stereotypes* represent collectively agreed upon beliefs about groups of people learned by most members of a social group. People can have knowledge of stereotypes without agreeing that the stereotypes are valid. *Prejudice*, on the other hand, is the agreement with a negative stereotype or belief. Unlike stereotypes, which are beliefs, prejudicial attitudes involve an evaluation that is generally negative. Prejudice also creates emotional responses (e.g. anger or fear) to stigmatized groups. *Discrimination* involves behaviors and actions that align with the negative belief.

[1] University of California-San Francisco Center for AIDS Prevention Studies, "How does stigma affect HIV prevention and treatment?" Accessed from: http://caps.ucsf.edu/archives/factsheets/stigma
[2] Vanable PA, Carey MP, Blair DC, Littlewood RA. Impact of HIV-Related stigma on health behaviors and psychological adjustment among HIV-Positive men and women. *AIDS Behav (2006) 10:473. Doi: 10.1007/s10461-006-9099-1.*
[3] Wisconsin Department of Health Services, 2016. "Be a Trauma-informed care champion!" Accessed from https://www.dhs.wisconsin.gov/publications/p01229.pdf
[4] Wisconsin Department of Health Services, 2016. "Trauma-Informed Care." Accessed from https://www.dhs.wisconsin.gov/tic/index.htm

Figure 1: Conceptual Framework for Elements of Stigma[5,6]



Because HIV prevention and care efforts are negatively impacted by stigma, actively and consciously avoiding language that can contribute to stigma, particularly labeling and stereotyping, is extremely important in working with clients and communities. Where stigma is present, discrimination (action generated from a place of stigma) frequently follows. HIV-related discrimination is the "unfair and unjust treatment of someone based on their real or perceived HIV status."[1] Populations disproportionately impacted by HIV face prejudice and discrimination based on one or more facets of their identity. These include the lesbian, gay, bisexual, transgender, queer/questioning (LGBTQ+) community; people who use drugs; people who experience poverty; sex workers; and people of color.[1] HIV-related stigma compounds stigma already experienced by these groups. When this happens, people are less likely to seek HIV testing and information, adopt safer behaviors, or disclose their HIV status to sexual partners.[7, 8]

To better understand how stigma and public health practice impact HIV-related outcomes, the National Alliance of State and Territorial AIDS Directors (NASTAD) and the National Coalition of STD Directors partnered in 2011-2012 to conduct a survey of more than 1,300 health department and community-based organization staff, health care providers, and community members representing U.S. states and territories. The results showed high levels of perceived stigma (at both community and institutional levels) directed at Black and Latino gay men/men who have sex with men (MSM).[9] Additionally, a focus group of health care providers and Black MSM showed that

[5] Meyerson B, Barnes P, Emetu R, *et al*. 2014. Institutional and structural barriers to HIV testing: Elements for a theoretical framework. *AIDS Patient Care and STDs* 28;1:22-27.
[6] Corrigan P, Watson A. 2002. Understanding the impact of stigma on people with mental illness. *World Psychiatry* 1;1:16-20.
[7] UNAIDS, 2014. Reduction of HIV-related stigma and discrimination. http://www.unaids.org/en/resources/documents/2014/ReductionofHIV-relatedstigmaanddiscrimination
[8] Earnshaw VA, Chaudoir SR. 2009. From conceptualizing to measuring HIV stigma: A review of HIV stigma mechanism measures. *AIDS Behavior* 13:1160-1177.
[9] NASTAD and NCSD, 2014. Addressing Stigma: A Blueprint for Improving HIV/STD Prevention and Care Outcomes for Black and Latino Gay Men. http://www.ncsddc.org/sites/default/files/nastad_ncsd_report_addressing_stigma_may_2014.pdf.pdf

certain language regarding HIV, sex, and sexuality can contribute to these levels of perceived stigma and is prevalent among health care providers. The focus group also noted that developing meaningful relationships with patients is important in engaging Black MSM with health care.[10] This is crucial since Black and other MSM communities of color are among those most impacted by HIV in Wisconsin and nationwide.

In alignment with a goal of the 2020 National HIV/AIDS Strategy to "reduce stigma and eliminate discrimination associated with HIV status,"[11] the Wisconsin AIDS/HIV Program is committed to ongoing training and critical discussion of its use of language. Learning to use person-centered language and other forms of compassionate communication is a process that takes time and practice. Part of this learning process is acknowledging when mistakes are made and learning from them. Even those with the best of intentions will sometimes use language that can contribute to stigma. The reality is that language that stigmatizes can lead to adverse outcomes regardless of the speaker's intentions. Ongoing training and education is also necessary due to the constantly evolving nature of language.

Training materials used by the AIDS/HIV Program have been adapted from The Stigma Project, a grassroots organization that "aims to lower the HIV infection rate and neutralize stigma through education via social media and advertising."[12] Examples of materials developed by the Project are presented in Figure 2 (images are hyperlinked).

Figure 2. Material Developed by The Stigma Project to Increase Awareness of Language that Contributes to HIV-Related Stigma

One tangible approach to avoiding language that could be perceived as stigmatizing is to shift to "person-first" language—where the person is mentioned before the identity or action. For example, instead of "an injection drug user," use the phrase "a person

[10] NASTAD webinar: The Power of Language and the Importance of its Appropriate Use. https://www.nastad.org/webinars/power-language-importance-its-appropriate-use

[11] National HIV/AIDS Strategy for the United States: Updated to 2020. Washington, DC: The White House Office of National AIDS Policy; 2-15. Accessed from: https://www.aids.gov/federal-resources/national-hiv-aids-strategy/nhas-update.pdf

[12] The Stigma Project. http://blog.thestigmaproject.org/

who injects drugs." Person-first language is important because it explicitly acknowledges the person as a human being first, and a possibly stigmatizing term is not a defining label. Another concrete approach is to simply update language that is inaccurate or out of date. Examples of commonly used phrases, reasons the language is inaccurate or stigmatizing, and alternative phrases to practice are listed in Table 1.

Table 1. Reducing HIV-Related Stigma through Language

Example of Inaccurate or Outdated Language	Reason Language is Ineffective or Could be Perceived as Stigmatizing	Example of Strength-based, Person-first, Trauma-informed Alternative
HIV patient, AIDS patient	These phrases put the virus or HIV status ahead of the person.	**Person living with HIV**
Positives		
Infected person		
AIDS or HIV carrier		
Victim, Innocent Victim, Suffers from HIV	These phrases negatively focus on victimhood or suffering instead of a person's ability to live a full, healthy life with HIV.	
HIV-infected mother	This phrase puts the HIV status ahead of the person.	**Mother living with HIV, Woman living with HIV**
Injection drug user (IDU)	When used to describe a person (rather than an HIV risk factor), this phrase puts the behavior ahead of the person.	**Person who injects drugs (PWID)**
Died of AIDS, to die of AIDS	These phrases demonstrate a lack of understanding of the virus, since a person cannot die of/from AIDS, and contribute to fear around HIV. HIV/AIDS is not a death sentence.	**Died of AIDS-related illness, AIDS-related complications or end stage HIV**
Full-blown AIDS	There is no medical definition for this phrase. "Full-blown" has a connotation that death is imminent and contributes to fear around HIV.	**AIDS, or Stage 3 HIV**
Mother to child transmission	This phrase carries undue emotional weight and can imply fault on the part of the mother transmitting HIV to her child.	**Perinatal transmission, vertical transmission**
Compliant	This word is usually used to refer to whether or not a person living with HIV is taking medication. 'Complying with' a doctor's recommendations puts the focus on the healthcare provider's orders; versus	**Adherent**

Example of Inaccurate or Outdated Language	Reason Language is Ineffective or Could be Perceived as Stigmatizing	Example of Strength-based, Person-first, Trauma-informed Alternative
	"adherent," which connotes the patient is empowered to actively follow their medication regimen for their own health.	
Prostitute or prostitution	These words are generally used to refer to criminal activity.	**Sex worker, sale of sexual services**
Promiscuous	This word implies a value judgment.	**Having multiple partners**
Unprotected sex	In HIV prevention, this phrase is generally used to refer to whether or not a person used a condom during sex and doesn't acknowledge that there are more ways to stay safer during sex.	**Sex without a condom, Condomless sex** **Also consider other methods of protection:** **- Pre-exposure prophylaxis (PrEP)** **- Viral suppression**
A transgender, transgendered	Transgender is an adjective for a gender identity.	**Transgender man, woman, or person, whatever pronoun the person prefers** In this case, transgender is said before person as it is an identity rather than a negative label.

Interventions and approaches to reduce stigma are needed at multiple levels. This will not only reduce stigma toward people living with and at risk for HIV, including gay and bisexual men/MSM, but will also improve sexual health outcomes for these groups. Introducing language that is non-stigmatizing into training for HIV providers is an important step toward operationalizing trauma-informed care. Use of non-stigmatizing language by providers will ultimately improve the delivery of services and increase the likelihood that persons will be retained in care or return for regular HIV/STI testing. This in turn will contribute to stopping the spread of HIV and achieving the goal of everyone living better, longer.