

**CAB Conference Call  
January 24, 2019  
12:00 EST  
Meeting Minutes**

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**Participants:**

<b>Alex</b>	FSTRF
<b>Andrea</b>	Jacobi Medical Center
<b>Andrew</b>	University of Colorado, Denver
<b>Brandon</b>	CAN Community Health
<b>Claire</b>	Harvard University
<b>Exzavia</b>	Children's Diagnostic and Treatment Center
<b>Fallon</b>	University of Colorado, Denver
<b>Gena</b>	University of Miami
<b>Jeanie</b>	University of Southern California
<b>Jennifer</b>	University of Colorado, Denver
<b>Joel</b>	University of Puerto Rico
<b>Juanita</b>	Tulane University
<b>Julie</b>	University of Alabama, Birmingham
<b>Julie</b>	Westat
<b>Kimbrae</b>	Texas Children's Hospital
<b>Kylie</b>	Texas Children's Hospital
<b>Latonia</b>	University of Illinois, Chicago
<b>Lawrence</b>	Harvard University
<b>Lesley</b>	Texas Children's Hospital
<b>Megan</b>	Westat
<b>Michelle</b>	Harvard University
<b>Raiko</b>	University of Colorado, Denver
<b>Shannon</b>	University of Alabama, Birmingham
<b>Stephanie</b>	University of California, San Diego
<b>Stephanie</b>	University of Miami
<b>Theresa</b>	Texas Children's Hospital
<b>Tracy</b>	Children's Diagnostic and Treatment Center
<b>Trinise</b>	Tulane University
<b>Veronica</b>	University of California, San Diego

• **APPROVAL OF MINUTES**

The minutes from the December 20, 2018 call were approved with no changes.

• **PEOPLE FIRST LANGUAGE**

**Valerie Wojciechowicz** talked about "people first language." **Valerie** works with **Brandon** as a Medical Peer Program Manager at CAM Community Health. Language around HIV can be stigmatizing. People first language is a way to reduce HIV stigma through language.

**Valerie** talked about the Denver Principles. The Denver Principles were the foundation for non-stigmatizing language for people living with HIV and AIDS. The authors of the Denver Principles suggested that people no longer talk about people living with HIV as "victims." They made recommendations for all people and for people living with HIV and AIDS. They also put together rights for people living with HIV and AIDS.

**Valerie** talked about the Meaningful Involvement of People With AIDS (MIPA). MIPA added another set of values. One of the principles of MIPA was to involve people living with HIV and AIDS in creating laws.

**Valerie** talked about people first language. People first language is a type of preferred language in English. The foundation of people first language is respect, dignity, and understanding. It aims to put the person *before* the diagnosis. People first language describes what the person *has*, not what the person *is*.

Many of the words describing HIV are stigmatizing. An example of people first language would be to say "person living with HIV" rather than "HIV-infected person." This is because the word "infected" can be thought of as a negative word. Other ways to refer to people living with HIV may include "people diagnosed with HIV" or "people who contracted HIV."

Some of the stigmatizing language surrounding HIV has to do with HIV treatment. If someone is not taking their medications they may be called "noncompliant." It is better to talk about a person's medication habits as adherence. "Adherent" is a less offensive term. Adherence is a more rewarding, pat on the back type of feeling. When someone is adherent, they are supporting the path of better self-care.

Other stigmatizing language can involve sexual activity. It is better to avoid terms such as "clean" as in "I'm clean." This implies that people living with HIV are dirty. The term "unprotected sex" can also be stigmatizing. To say someone needs to be protected is making people with HIV feel dangerous. A better term is "condomless sex."

The term "sero discordant" is meant to describe couples where one person is living with HIV but the other is not. This term can be stigmatizing because it means a lack of harmony. Better terms include "serodifferent" or "mixed status."

The term "full blown AIDS" is very stigmatizing. There is no medical definition for "full blown AIDS." AIDS is defined in its own acronym as acquired immune deficiency syndrome.

HIV has its own culture, history, and community. People living with HIV deserve respect. Respect can start with the way people speak to, about, and refer to someone living with HIV. People first language empowers people living with HIV to take power back and away from words that stigmatize. People first language asks people to think before speaking. People living with HIV are a community; they are not just patients or clients, and not just a diagnosis.

**Stephanie** talked about people first language. **Stephanie** plans to share the presentation with the CAB members at her site. She encouraged other CAB members to spread the information to others. **Valerie** encourages other to share but explained that it can be difficult to share information about people first language. Sometimes people living with HIV do not accept the language suggestions easily.

**Gena** talked about language suggestions. **Gena** discussed stigmatizing language in the National Minority AIDS Council Building Leaders of Color program. **Gena** explained that people can use confrontational situations to educate people. When someone disagrees, one can use it as an opportunity to introduce them to new language terms.

**Jennifer** talked about people first language. **Jennifer** asked about how people first language affects prevention efforts. Does it lessen concern about HIV? Does it empower people to know their status? **Valerie** explained that scare tactics do not always work. People first language can empower people. In general, non-stigmatizing language makes it easier to talk about HIV. **Stephanie** talked about non-stigmatizing language. If language surrounding HIV was less stigmatizing, more people would be willing to talk about HIV. More people talking about HIV could help prevention and treatment efforts.

**Andrew** talked about non-stigmatizing language. Negative terms are hurtful and keep people from talking about HIV. **Claire** talked about people first language. **Claire** asked about presenting the concept of people first language to healthcare professionals. **Valerie** explained that all people can benefit from people first language. It is especially important that healthcare professionals use less stigmatizing language. It is a work in progress.

- **COLLABORATION WITH THE PHACS WORKING GROUPS**

**Megan** talked about collaboration with the PHACS Working Groups (WGs). At the PHACS Fall 2018 Networking Meeting, many CAB members and WG Leaders expressed an interest in finding better ways to collaborate. The CAB was encouraged to think of ways to collaborate with WGs. **Megan** talked about ways the CAB has collaborated with WGs in the past. These included inviting WG Leaders to join CAB calls, inviting CAB members to attend WG calls, scheduling separate calls to discuss specific questions, and emailing materials to CAB members for review.

**Kim** suggested that WG Leaders continue to involve CAB members. One way could be for WG Leaders to send discussion questions to **Megan**. **Megan** could then bring the discussion questions to the CAB calls or email individual CAB members.

It was suggested that when WG Leaders join CAB calls they send discussion questions to the CAB ahead of time. This has helped CAB members prepare for the presentation. It was also suggested that WGs consider involving site CABs. WG Leaders could pass discussion questions on to site CAB Leaders to present to their site CABs. Site CAB Leaders would be asked to relay feedback back to the WG Leaders.

It was suggested that CAB members participate as ambassadors to WGs. The ambassadors would be the primary person who communicates with **Megan** and the WGs. The ambassador and **Megan** would help present discussion questions or topics on CAB calls. **Kim** suggested that it may be helpful for **Megan** to be the liaison with the WGs and involve CAB members as ambassadors on a volunteer basis.

**NOTE: The next CAB call will be on Thursday, February 28, 2019 at 12:00 pm EST.**