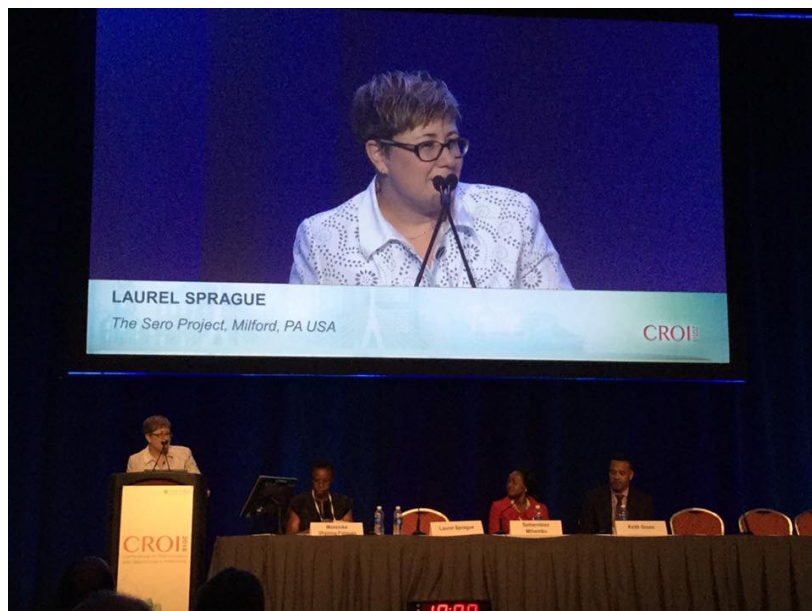


Limits and Complexity: Research on Stigma and HIV
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Remarks for the Martin Delaney Panel at CROI 2016

I am a woman who has been living with HIV for 25 years. Having somehow survived a number of alternative therapies, about which I will spare you the details, and AZT monotherapy, I have been deeply grateful to Martin Delaney for decades for his commitment to research and communities. It is an honor to be here.

In the spirit of Martin Delaney, I would like to briefly speak about community engagement in HIV stigma research, building on the work of many, many researchers both academic and community-based, living with HIV or not HIV-positive.

What is HIV-related stigma?

Stigma is a social process by which some people, based on their characteristics, are perceived to be less valuable and are excluded from social regard and power. Others, those without this characteristic, are treated as more valuable human beings.

HIV-related stigma includes mistreatment for being HIV-positive as well as stigmas that intersect with HIV, including racism, homophobia, transphobia, sexism, bias against the poor, bias against immigrants, and others.

There is a political aspect to stigma.

My understanding of the politics of stigma arises from the work of W.E.B. Du Bois and his 1935 definition of a **psychological wage**. This wage refers to the psychological benefit that even poor white people received, for being white in the U.S., that maintained racism and kept them from standing in solidarity with African Americans.

In terms of the politics of HIV-related stigma: those who feel a bit more respectable, “cleaner,” more credible, because they are not HIV-positive have some incentive to keep stigma in place.

Two research programs on HIV stigma

Since 2009, I have been involved with two community-based research programs on HIV-related stigma:

The largest of these is the **People Living with HIV Stigma Index**. The Stigma Index is a collaborative effort between the Global Network of People Living with HIV, the International Community of Women living with HIV, and the Joint United Nations Programme on HIV/AIDS. This is a research and action project, in which people living with HIV are trained to manage the project; interviewer other people with HIV; understand, analyse and use the results; and lead advocacy work that results

from the study. The Stigma Index has been implemented in more than 50 countries and includes partnerships with academics, government, and health care providers.

The findings of the Stigma Index vary by country, but reveal common themes. For example, denial – within the last 12 months - of care by health providers is reported by 10-40% of respondents. Social exclusion, gossip, family exclusion, and violence are often high. Internalized stigma is always high.

The results of the Stigma Index have included PLHIV-led programs with hospitals, prisons, employers, and governments and advocacy efforts, too numerous to list here, by and for people living with HIV.

My other stigma-related research has been with the **Sero Project**, a network of people living with HIV formed to address HIV-related stigma, particularly criminalization of people with HIV. We created a survey in 2012 to explore how people with HIV perceived the rightness or wrongness of HIV-specific criminal laws and how these laws affected them. Approximately 3000 people living with HIV in the US responded.

Respondents described deep-level vulnerabilities created by legal systems. Laws related to HIV are obtusely written and arbitrarily exercised. People living with HIV did not feel clear about what behaviors were prohibited. Large percentages of respondents feared false accusations of non-disclosure and the general consensus was that a person with HIV could not get a fair trial if accused.

Why involve communities in HIV stigma research?

Of course, there should be some obvious impulses to

- **protect the dignity of human beings rather than treating them solely as research specimens**

--- and to -----

- **refuse to perpetuate the notion that stigmatized people have nothing of value to contribute**

Beyond these ethical imperatives, there are practical reasons to involve communities. I am going to talk about two and illustrate each with a story.

The first practical reason to involve communities is: **to get your questions right.**

In the Sero Project's HIV criminalization survey, we wanted to explore a question that seemed ubiquitous in academic research studies on this issue:

Should it be illegal for HIV-positive people to have unprotected sex without disclosing their HIV status?

Respondents generally said yes, including majorities of gay men and even people living with HIV.

In a time period and a country marked by mass incarceration, these responses were concerning.

And, as people living with HIV who were involved in many community conversations about stigma and criminalization, we felt that the respondents were answering a different question than that posed. We wondered if respondents were saying: yes, people generally should not lie to their intimate partners about issues that might affect their health. But did this mean they truly supported **prosecution**?

So we tested this in our survey. First, we asked the usual question, “*Should it be illegal...*”. The response?

Similar to the other surveys more than half of our respondents agreed that non-disclosure should be illegal.

Then we asked the question differently. We asked:

In general, would you consider disclosing one’s HIV positive status as:

- An ethical or moral obligation
- Dependent on the specific circumstances
- A desired community norm
- Something you automatically expect a person living with HIV to do
- A legal matter for civil courts
- A legal matter for criminal courts
- Desirable but not something that should be a law
- No more or less important than disclosing other STIs
- Important only if engaging in behaviors that pose a serious risk of HIV transmission

Respondents were allowed to select every answer with which they agreed. When given these options, it was no longer the case that a majority of respondents supported criminalization. Instead, **only 11% indicated that prosecution was appropriate.**

My second story illustrates the other practical reason to partner with affected communities. First, you have to get your questions right. Then you also need: **to get your answers right**

About 20 years ago, I attended a research presentation about HIV transmission and lesbians. Lesbians living with HIV, including me, were desperate to understand transmission risks.

The researchers shared survey results indicating that HIV-positive lesbians rarely practiced safer sex. The recommendation: more education!

Without the engagement of our communities, they misunderstood their results. Instead of telling lesbians to practice safe sex, what was needed was **evidence of the likelihood of transmission between women** and not the assumption that their research subjects lacked education or concern for their partners.

What a waste of resources.

Challenges and complexities

Let me instead close my remarks with a few comments on the challenges and complexities of conducting stigma research within community-academic partnerships.

First of all, **everyone has to slow down to make partnerships work**. It is difficult with the urgency for results that communities feel and with the funding deadlines that academics face. However, we do not always work the same ways, talk or communicate in the same ways. Slowing down is necessary.

For community members who participate in these partnerships, there is a toll. Tokenism is still too common, and too often you realize that you are the only person in the room with HIV. Not only is that lonely but you are often treated as if you can speak for all others.

Being in a room examining the harmful things that are said about you and people you love – in order to do the important work of measuring and responding to stigma – takes an emotional toll. If you are a researcher/academic, try to remember that the emotional work of being in the room is harder for some than others.

Further confidentiality matters. Just because a person with HIV participates in a research partnership does not mean that her or his HIV status can be shared with others. Permission is still required.

Others issues with community-academic partnerships include a distinct power imbalance in funding. Community research is devalued when funding is given out. Further, there can be exploitation of community voices when members are invited to an advisory body but not provided any influence on the design, implementation, or analysis.

In the effort by researchers to ensure community representation, it is essential to ensure that the people you bring on board actually belong to a community. You cannot keep pulling people in off the street or because you happened to meet them somewhere and then assume that you have community representation. You need to connect with networks of people living with HIV and community organizations. Again, there are no short cuts. We all have to slow down and build relationships.

Finally, we need to think about evening out the research benefits. Think about what researchers are getting? What is the community getting? Have conversations so there is clarity about what it is that community members want and that researchers want.

Thank you very much for the opportunity to speak with you today.