the NETWORK for LGBT tobacco control

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Public Testimony

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National Advisory Council on Minority Health & Health Disparities

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September 13, 2010

Dear Colleagues:

I welcome this opportunity to humbly submit public comments for consideration of the National Advisory Council on Minority Health and Health Disparities.

First, let me present some of my background. I am a researcher/advocate working to reduce lesbian, gay, bisexual and transgender (LGBT) health disparities. I am the Director of one of the six CDC tobacco disparity networks, The Fenway Institute's Network for LGBT Tobacco Control. I also hold adjunct appointments as the Director of Science Policy for the National Coalition for LGBT Health, Boston University School of Public Health, and The Center for Population Research in LGBT Health (LGBT Pop Center). To keep this brief, let me just say that I been consulting for various federal agencies since the early 90s and I have extensive history with extramural researchers specializing in LGBT health, in traditional racial/ethnic minority disparities, and with the intersection of both of those populations. My CV is attached if you desire more details.

As you well know, federal health research dollars fuel the engine which generates much of our disparity knowledge today. Unfortunately, I must convey my sincere concern that in too many instances, *these funding streams are not welcoming to legitimate research focusing on LGBT disparities*. This has the effect of stifling the cadre of researchers, the knowledge base, and ultimately, the deployment of tested interventions to reduce these disparities.

LGBT health disparities have been recognized as a legitimate problem in federal health policy documents for over a decade. Healthy People 2010,[1] the 2006-7 President's Cancer Panel report[2], and the 1999 IOM Report on Lesbian Health[3] are all examples of historic policy documents calling for

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more activity in this area. The forthcoming IOM report on LGBT health disparities will marshal the very latest evidence of decades of substantive research demonstrating a pattern of health inequity for the LGBT population that is profound.[4] In case you are unfamiliar with the magnitude of the problem, consider these few facts:

- The LGBT population smoking prevalence is from 35% to almost 200% higher than the general population.[5] [6]
- In the largest transgender survey to date, fully 25% of respondents report being *refused* medical care.[7]
- LGBT youth attempt suicide at rates that are up to three times higher than non-LGBT youth.[8] [9]

Considering the body of evidence on LGBT health disparities, you can understand my dismay at realizing many funding streams are not welcoming to LGBT health research.

Why do I claim these funding streams are not welcoming? Let me first review a piece of history. In 2003, a right-wing group called for a list of federal research projects to be defunded.[10] Included in this list were many LGBT health and HIV-related projects. Some researchers literally left the field after months of public scrutiny and the stress of any minute being called to defend their research in front of Congress. Many of the researchers who are prominent today were sincerely affected by that public declaration of their vulnerability. At a recent gathering of the LGBT Pop Center faculty, I was struck by how intensely many of the researchers were shaped by that era; in the words of one, "I still have post-traumatic stress from it today."[11] This chapter of history is not exceptional, it is simply the most public example of a less visible chilly climate towards LGBT health at several levels of the Department of Health and Human Services (HHS). Researchers routinely discuss being asked to hide the LGBT focus in their NIH proposals (there is evidence of this as recently as 2009[12]), having to deal with review panels with no expertise on the population, or of flat out being informed that LGBT focused research was not welcome.

Make no mistake, many HHS staff have made a yeoman's effort to address LGBT disparities in spite of this chilly climate. One of many such examples is the staff at the Centers for Disease Control and Prevention (CDC) who released the RFA for the tobacco disparity networks. After the Office of Management and Budget refused to approve an RFA that continued funding for an LGBT network, CDC staff created alternate language (for a "wildcard" category) that allowed the LGBT network to continue. But it means to this day the LGBT tobacco network will only exist if an applicant bests all other comers in this "wildcard" category, which is amazing considering research consistently demonstrates the LGBT population has record high smoking rates.[13]

Likewise, please understand there are recent changes at HHS heralding a new level of LGBT disparity inclusion, for example: the convening of the new cross-HHS LGBT task force, the development of an LGBT Workgroup for Healthy People 2020, and the commissioning of the aforementioned IOM report on LGBT health.

Let me return to the issue for which you are meeting, the work of the National Center for Minority Health and Health Disparities within NIH. I had the pleasure of meeting with Dr. Ruffin last year.[14] At that meeting he personally assured me NCMHD was welcoming to LGBT health disparity research and projects. I am very heartened to hear this, and would expect no less from this august body.

Unfortunately, I must honestly report that in my dealings with LGBT health researchers, there is a strong perception that NCMHD is the opposite and not welcoming to LGBT research and projects.

I was recently attempting to cajole prominent LGBT faculty from the LGBT Pop Center to submit applications to NCMHD, and to a one, they refused to even consider the possibility because of this reputation. Due to the burden in developing an NIH application, they quite reasonably focus on responding to RFAs with some history or personal assurance of being welcoming.

The evidence appears to support their concern. In doing a search of NIH's rePORT, I find 563 funded projects by NCMHD, and of these, only two report targeting some portion of the LGBT community; for each it is African American men who have sex with men (MSM).[15]

The most recent strategic plan on the NCMHD website is for FY 2004-8. In this document it records that a major theme in the 2003-4 public comment period for the prior plan was to expand the target populations to include (among others) LGBT people.[16] The response in the plan was as follows:

> "In the future, as the NIH Health Disparities Strategic Plan is revised and updated over the years, and based upon the Institute of Medicine (IOM) Report described below, the NCMHD will work with the Agency for Healthcare Research and Quality to determine whether other populations meet this definition and should be designated as health disparity populations. Thus, future iterations of the plan will reflect the evolution of the development of health disparity populations." (vol. 1, p.11)

It is now 2010; to my knowledge there has not yet been a consideration of formal expansion to include LGBT people in the main focus of NCMHD. While there is informal expansion and welcoming of LGBT focus, you can understand, the history of discrimination renders this informal change less effective than desired.

I know every person on the National Advisory Council has dedicated a majority of their lives to eliminating health disparities in every form. As a newer researcher, I stand on the work done by yourself and others. I hope you consider the information and appeal I have laid out in this testimony. In my opinion, creating a welcoming environment for LGBT research at NCMHD & NIH will both create needed improvements for many LGBT individuals and add strength to the field of disparities research.

In solidarity,

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Director, National LGBT Tobacco Control Network

Citations

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[10] Epstein S. (2006) The new attack on sexuality research: Morality and the politics of knowledge production. Sexuality Research and Social Policy, Volume 3, Number 1, 1-12.
[11] Personal communication, July 2010. I can provide details of the stating scientist if it is needed and they agree to disclose their identity.
[12] Evidence of the 2009 example can be provided upon request.
[13] This example can be verified by comparing RFA: CDC-RFA-DP08-811 with the 2000-2005 version of the same funding opportunity.
[14] Telephone meeting on March 13, 2009. Between Dr. Ruffin and the joint heads of the tobacco disparity networks.
[15] Search done on http://projectreporter.nih.gov/reporter.cfm on September 13, 2010. Search criteria: NCMHD projects v. NCMHD projects that included keywords 'gay' or 'lesbian' or 'bisexual' or 'transgender'.
[16] NATIONAL INSTITUTES OF HEALTH U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES. NIH Health Disparities Strategic Plan, Fiscal Years 2004-2008 Volume I. Downloaded from http://ncmhd.nih.gov/about_ncmhd/index2.asp on September 13, 2010.