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July 26, 2012

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Dr. John Ruffin  
Director  
Institute for Minority Health and Health Disparities  
National Institutes of Health  
6707 Democracy Boulevard, Suite 800  
Bethesda, MD 20892-5465

Dear Dr. Ruffin,

We are writing on behalf of The Leadership Conference on Civil and Human Rights, a coalition charged by its diverse membership of more than 200 national organizations to promote and protect the civil and human rights of all persons in the United States, and the undersigned organizations, regarding the definition of "health disparity population" overseen by the Institute for Minority Health and Health Disparities. We understand that this definition is currently being revised under your direction by the National Advisory Committee for Minority Health and Health Disparities, and we wish to express our support for a revised health disparity population designation methodology that draws on the existing evidence base on lesbian, gay, bisexual, and transgender (LGBT) health disparities and leads to the LGBT population being formally designated as a health disparity population.

In the Minority Health and Health Disparities Research Education Act of 2000, Congress declared that "a group is defined as a health disparity population if, as determined by the Director of [NIMHD] after consultation with the Director of the Agency for Healthcare Research and Quality, there is a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality or survival rates in the population as compared to the health status of the general population."

According to the Department of Health and Human Services, LGBT communities, like other underserved populations, face unique health challenges, have reduced access to health care and insurance, and often pay the price with poorer health throughout their lives.<sup>i</sup> Sources from across the department, such as Healthy People 2020,<sup>ii,iii</sup> the Office of Minority Health,<sup>iv</sup> and the Agency for Healthcare Research and Quality,<sup>v</sup> indicate that the LGBT population experiences significant disparities in health indicators such as smoking, obesity, experiences of abuse and violence, mental health concerns such as suicide, and HIV infection.

The Institute of Medicine (IOM), in its comprehensive review of LGBT health research released in 2011, also found that LGBT individuals experience significant health disparities.<sup>vi</sup> According to the report, LGBT people share the full range of

July 26, 2012

Page 2 of 5

health risks with the general population and also face profound additional health risks due largely to prejudice and social stigma. The report emphasizes that these disparities are frequently exacerbated by other discriminatory social forces, such as racism.

Unfortunately, the IOM found that the LGBT population is often invisible to health researchers and health care providers and that this invisibility compounds the negative effects of stigma and discrimination. NIMHD can take a vital step in addressing this invisibility by ensuring that the revised health disparity population designation methodology accommodates existing research on LGBT health disparities and leads to the LGBT population being formally designated as a health disparity population.

This should involve ensuring that any set of benchmark health indicators used in the methodology include indicators relevant to LGBT populations, such as HIV/AIDS, tobacco use, and mental health concerns. It also must include explicit recognition of how a more robust LGBT health research agenda, including methodological research into how to most effectively investigate the health disparities affecting particularly marginalized segments of the LGBT population, such as LGBT communities of color, transgender individuals, LGBT people with disabilities, and rural LGBT people, will enhance our current understanding of LGBT health disparities and lead to more targeted and effective strategies for addressing these disparities.

Designating the LGBT population as a health disparity population will help NIH pursue concrete actions for addressing LGBT health disparities. According to the IOM, these actions should include:

- Developing a robust and diverse research agenda in LGBT health, including methodological research, that is better integrated into ongoing research agendas in a variety of fields and into researcher training programs than previous NIH program announcements in the field of LGBT health;
- Expanding researcher training programs to include researchers who are currently working with or who want to work with LGBT populations, researchers who may not be aware of LGBT health issues, and NIMHD and other NIH staff;
- Encouraging NIH grant applicants to explicitly address how and why their proposed research includes or excludes LGBT individuals; and
- Developing standardized sexual orientation and gender identity measures for federally supported surveys.

All of these activities would support and strengthen existing initiatives at NIMHD, such as research into HIV/AIDS prevention for young gay, bisexual, and other men of color who have sex with other men, as well as initiatives at the Office of Minority Health that explicitly focus on both LGBT communities of color and the LGBT population at large. This work includes funding re-entry programs for formerly incarcerated HIV-positive individuals that encourage grantees to include transgender women of color as a priority population, and supporting the development of questions on sexual orientation and gender identity for national health data collection instruments such as the National Health Interview Survey.



July 26, 2012

Page 3 of 5

Moreover, until sexual orientation and gender identity are formally recognized as factors associated with health disparities, researchers, service providers, and others working to address LGBT health disparities will continue to have severe difficulty building a substantial research agenda and attracting the resources necessary to support their efforts. Designating the LGBT population as a health disparity population is a crucial part of promoting a comprehensive understanding of health equity for diverse disadvantaged communities and focusing attention on the additional investments needed in efforts to eliminate health disparities not just for LGBT communities but across the board.

As representatives of advocacy organizations deeply concerned with promoting health equity and eliminating health disparities, we understand that health disparity populations are diverse and that racial, ethnic, socioeconomic, and other disparities cannot be fully addressed in isolation from the disparities associated with stigmatized sexual orientation and gender identity. We therefore urge you to formally designate the LGBT population as a health disparity population as part of the current process of revising the definition of these populations. We look forward to discussing this matter with you, and we thank you for your attention to this issue and your commitment to eliminating health disparities across our nation.

Sincerely,

9to5, National Association of Working Women

AARP

American Civil Liberties Union

American Association of University Women (AAUW)

AFGE, Women's and Fair Practices Department

American Public Health Association

A. Philip Randolph Institute

Asian American Justice Center, member of Asian American Center for Advancing Justice

Asian & Pacific Islander American Health Forum

Center for American Progress

Community Action Partnership

Disability Policy Consortium

Disability Rights Education & Defense Fund

Family Equality Council

Human Rights Campaign

The Leadership Conference on Civil and Human Rights

League of United Latin American Citizens

July 26, 2012

Page 4 of 5

Mental Health America

NAACP

National Association of Colored Women's Clubs, Inc. (NACWC)

National Association of Human Rights Workers (NAHRW)

National Center for Transgender Equality

National Coalition for Asian Pacific American Community Development (National CAPACD)

National Community Reinvestment Coalition

National Council of Jewish Women

National Council of La Raza

National Fair Housing Alliance

National Gay and Lesbian Task Force

National Health Law Program

National Organization for Women

National Partnership for Women & Families

National Senior Citizens Law Center

National Women's Law Center

CC:

Dr. Francis Collins

Dr. Lawrence Tabak

Dr. Francisco Sy

Dr. Nathan Stinson

Dr. Nadine Gracia

Dr. Howard Koh

Ken Choe

Kathy Greenlee

Dr. Sherry Glied

A.J. Pearlman

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<sup>i</sup> U.S. Department of Health and Human Services (2011). "Improving Data Collection for the LGBT Community." Available from <http://www.healthcare.gov/news/factsheets/2011/06/lgbt06292011a.html>

<sup>ii</sup> "If a health outcome is seen in a greater or lesser extent between populations, there is disparity. Race or ethnicity, sex, *sexual identity*, age, disability, socioeconomic status, and geographic location all contribute to an individual's ability to achieve good health." (Healthy People 2020, "Disparities," <http://www.healthypeople.gov/2020/about/DisparitiesAbout.aspx>)

<sup>iii</sup> "Research suggests that LGBT individuals face health disparities linked to societal stigma, discrimination, and denial of their civil and human rights... Eliminating LGBT health disparities and enhancing efforts to improve

July 26, 2012

Page 5 of 5

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LGBT health are necessary to ensure that LGBT individuals can lead long, healthy lives.” (Healthy People 2020, LGBT Health Topic Area, <http://healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=25>)

<sup>iv</sup> “a body of evidence continues to expand, which documents the existence of other health disparities by, for example, gender, literacy level, **sexual orientation or gender identity**, disability status, geography, and age.” (*The National Stakeholder Strategy for Achieving Health Equity*, <http://minorityhealth.hhs.gov/npa/files/Plans/NSS/NSSExecSum.pdf>)

<sup>v</sup> “AHRQ’s priority populations, specified by Congress in the Healthcare Research and Quality Act of 1999, are [list of populations]... Other populations, **such as LGBT**, are also included.” (*National Healthcare Disparities Report 2011*, <http://www.ahrq.gov/qual/nhdr11/nhdr11.pdf>)

<sup>vi</sup> Institute of Medicine (2012). *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*. Washington, DC: The National Academies Press. Available from <http://www.iom.edu/Reports/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People.aspx>