

Guiding Principles for LGBT Inclusion in Healthcare Reform

As Congress and the Obama Administration undertake reform of the American healthcare system to ensure that all Americans have equitable access to the full continuum of health promotion, prevention, and treatment services, we must be sure to effectively address the needs of distinct populations, especially those with demonstrated health disparities. As more than 75 local and national organizations committed to the health and well-being of lesbian, gay, bisexual, and transgender (LGBT) individuals, we endorse the following principles regarding full inclusion of LGBT concerns at all level of the process of healthcare reform. We hope that they will guide and inform your work as you begin shaping and implementing the project of healthcare reform.

For lesbian, gay, bisexual, and transgender (LGBT) people, social stigma and systemic discrimination based on sexual orientation and gender identity and expression have led to decades of obstructed access to adequate LGBT-affirmative and culturally competent healthcare and have had significant negative impacts on the overall health of LGBT individuals. LGBT people suffer disproportionately from the adverse health effects of stigma, stress, and violence, further compounded by the barriers that prevent them from accessing vital healthcare services even for routine care: research has consistently shown that being LGBT substantially impacts whether or not a person receives care and, when they do receive care, whether that care effectively speaks to all aspects of their lives. In order to begin to address these disparities, any healthcare reform must be fully LGBT-inclusive.

Healthcare disparities affecting the LGBT community are now recognized by numerous federal agencies and working groups, including the following divisions of the US Department of Health and Human Services (HHS): the Substance Abuse and Mental Health Services Administration (SAMHSA), the Health Resources and Services Administration (HRSA), the Centers For Disease Control and Prevention (CDC), and the National Institutes of Health (NIH). The HHS Secretary's Advisory Committee on Healthy People 2020 has acknowledged the imperative to address the disparities in health status and healthcare access that affect the LGBT community, as well as the necessity of targeting the specific needs of the LGBT community when undertaking healthcare system reform.

In addition, LGBT health disparities must be addressed across multiple communities rather than in isolation. Many members of the LGBT community are members of other communities that also face substantial health disparities and are thus vulnerable to cumulative negative outcomes. For example, an African-American gay man will face disparities common to the African-American community as well as those suffered by the LGBT community, and a transsexual Spanish-speaking woman, regardless of her sexual orientation, must navigate multiple instances of discrimination based on language, ethnicity, and gender. LGBT individuals need to have access to healthcare services that are sensitive to and inclusive of all their issues and concerns. Therefore, any panel, program, or system that focuses on communities with health disparities (e.g. racial,

ethnic, or geographic populations) must also fully incorporate LGBT concerns, and attention to LGBT issues must be seen as integral to addressing the interlocking systems of vulnerability and need that result in health disparities.

To eliminate health disparities in the LGBT community and to improve the health of all people in America, all legislative actions and government policies must fully embrace the LGBT community, and healthcare reform must establish and implement clear guiding principles based on solid clinical standards integrated with a compassionate understanding of the healthcare issues facing this vulnerable population. The following statements of principle are provided for consideration in the development and full implementation of healthcare reform. The areas framed below are specific to the LGBT community, yet they also have application to groups such as heterosexual individuals, people of color, recent immigrants, and nontraditional families, all of which interact with and often share constituents with the LGBT population. We believe these principles are crucial elements of effective, comprehensive, evidence-based healthcare reform for the LGBT community. They are not listed in priority order: all are important, and many are interdependent.

- ***Guarantee Access to Care:*** Enacting healthcare coverage for everyone in the United States is a particularly important step in eliminating healthcare disparities for the LGBT population. The current system of employer-based coverage is a barrier to many, since so few employers extend coverage eligibility to same-sex partners. In addition, the lack of employment protections based on gender identity and expression results in a high rate of unemployment in the transgender community and further reduces access to insurance coverage.

LGBT individuals and their families must be able to access the full range of services they require, delivered by providers who are sensitive to their needs, and any form of healthcare that is regulated or monitored by the federal government must be required to be permanently LGBT-inclusive. Accordingly, an oversight body or some other decision-making power must be established so that access to healthcare and specific services cannot be summarily removed by anti-LGBT administrations or officials. Furthermore, every commission or other body responsible for review of healthcare policy must include individuals with expertise regarding LGBT healthcare and health disparities.

- ***Include Our Identities and Families in Policy and Legislation:*** Regulatory, programmatic, policy and/or legislative definitions must be written to remove barriers that prevent LGBT individuals from accessing healthcare. In particular, the terms “family,” “parent,” and “spouse” are commonly interpreted to exclude LGBT families on the basis of a lack of access to the rights and benefits of legal marriage. For example, as long as the federal government’s definition of families is exclusive of LGBT households, same-sex partners who have entered into domestic partnerships and civil unions will not be able to access healthcare through programs designed to cover families, such as the State Children’s Health Insurance Program (SCHIP).

As a first step towards remedying this situation, we urge Congress and all agencies and or entities overseeing healthcare reform to implement LGBT-inclusive definitions of family. Current sick leave regulations for federal employees offer an excellent example by defining “family member” to include “any individual related by blood or affinity whose close association with the employee is the equivalent of a family relationship.”¹ In addition, social welfare policies impacted by healthcare reform efforts must recognize and support the existence of many types of family units, including single parents, same-sex parents, and transgender parents. Policies must also address the welfare of LGBT youth and dependent adults (e.g. their need to be placed in families or custodial or long-term care settings that support their LGBT identities and healthcare needs). Without supportive family or other living structures, many LGBT youth and adults alike will be denied access to services that fulfill their healthcare needs.

- ***Do Not Exclude Based on Diagnoses of Pre-Existing Conditions:*** Due to widespread employment discrimination and lack of relationship recognition, LGBT people are more likely to be without prior insurance coverage and are thus disproportionately affected by practices that preclude or limit coverage based on pre-existing conditions. Many transgender individuals with a previous diagnosis or history of treatment for transsexualism report being excluded outright from purchasing even basic individual coverage for routine care. In addition, due to experiences of stigma or discrimination, LGBT individuals are less likely overall to have accessed ongoing preventive healthcare or early diagnostic services. For both physical and mental conditions that exact a high toll in the LGBT population, late diagnosis and treatment lead to a higher prevalence of serious, advanced-stage disease and ultimately to excessive mortality. As we move to reform our healthcare system, we must ensure that pre-existing conditions do not continue to negatively impact the ability of LGBT individuals to secure or retain healthcare coverage for necessary medical services.
- ***Include Mental Health Parity:*** Any healthcare reform must have fully inclusive mental health coverage. Research has shown that the LGBT population is seriously impacted by mental health concerns and substance abuse issues due to the pervasiveness of discrimination and the stresses of living with societal homophobia, biphobia, and/or transphobia. Mental health services should be covered at the same levels as physical health services, and parity should extend to service limits, maximum spending caps, and cost-sharing levels.
- ***Mandate the Implementation and Practice of Cultural Competency:*** Providers in the healthcare system must fully understand and embrace cultural competency. Universal access to healthcare will have little meaning for many LGBT individuals if they cannot access care from culturally competent professionals who recognize and affirm their identities. There must be systematic efforts to remove healthcare provider biases: too often, LGBT people are misunderstood, mistreated, or openly discriminated against by healthcare providers.

The federal government must provide and promote training, funding, best practices, and awareness programs about LGBT people and their specific health needs. Furthermore, broad legal and regulatory protections must be put in place for LGBT people who disclose their sexual orientation and/or gender identity in healthcare settings. Without fear of negative repercussions, LGBT individuals are more likely to be comfortable speaking with healthcare providers about their lives, including their sexuality and gender identity. Opening these channels of communication is key to eliminating disparities, improving care, and bettering the overall health status of LGBT individuals.

➤ ***Create Appropriate Data Collection Tools for All Populations to Facilitate Proper Planning, Clinical Care, and Program Evaluation:*** Historically, health data collection efforts have not included LGBT populations or gathered information regarding the specific healthcare needs of LGBT people. Consequently, all new or updated national forms or data collection tools must be inclusive of diverse sexual orientations and gender identities. For example, forms must include the ability to choose a same-sex partner versus a spouse, or to choose "transgender female" or "transgender male" (or other transgender-inclusive identification options that may be determined by researchers) under any demographic gender questions, or for an individual to name "parent 1" and "parent 2" as opposed to "mother" and "father." In addition, all efforts to track or redress health disparities must include LGBT people as a health disparities population, and efforts to identify cost-effective healthcare protocols must include sensitivity to the health needs and outcomes of the LGBT community.

➤ ***Ensure that Health Information Technology Maintains Appropriate Levels of Privacy and Confidentiality:*** Health information technology must employ adequate safeguards in order to protect patients' privacy. While information about an individual's sexual orientation and gender identity should be collected as part of his/her routine medical history, unauthorized and/or unprotected disclosure in medical records could harm an LGBT person's access to healthcare. For example, a transgender woman may need to permanently change her gender marker from "male" to "female," yet medical records may need to indicate that she still requires a prostate exam by her primary care provider.

Health information technology provisions must safeguard against accidental release of information and also ensure that healthcare providers do not use information kept in electronic medical records to discriminate against LGBT people, either by refusing to provide certain services or by providing substandard care. In addition, agencies or entities engaging in reforms to healthcare involving health information technologies must actively include experts in LGBT health in any decision-making process.

➤ ***Mandate Healthcare Coverage and Services for Transgender Individuals:*** Gender-variant people must be afforded access to basic healthcare that

acknowledges their gender identity without prejudice or adverse consequences. Many insurance plans still routinely refuse coverage for many medically necessary services by excluding “transgender-related services” and denying coverage for any medical expenses that could be interpreted as relating to “sex reassignment.” Such exclusions are frequently expanded by insurance carriers and healthcare providers to deny coverage for conditions--even life-threatening conditions--that are not related to transsexualism. Many routinely deny coverage for services that do not match the recorded gender: female-to-male transsexual people may be refused coverage for gynecological care, and male-to-female individuals may be denied coverage for prostate exams. Such policies deter individuals from seeking treatment, including primary care, for fear that their transsexual status could be revealed and cost them their insurance or ability to access care in the future.

The American Medical Association (AMA) has explicitly called for public and private insurers to cover medically necessary services related to transsexualism.² The procedures used in transition-related care for transsexual people have been in use for decades and are not new or experimental, and similar services are routinely covered for non-transsexual people. Thus, healthcare reforms must extend coverage for all medically necessary treatments and procedures, including those required by transgender individuals, regardless of whether these services are related to transsexualism.

- ***Provide Inclusive Reproductive Healthcare Services:*** Government policies must support every LGBT individual’s personal authority and right of self-determination over their own sexual life, fertility, and reproductive capacity, in contexts that are free from coercion, violence, or discrimination. Every individual must have access to family planning, abortion, and reproductive health information and services, including contraception; fertility enhancement; prevention and treatment of HIV/AIDS and other sexually transmitted infections (STIs); and prenatal, birthing, and postpartum care.
- ***Address the HIV/AIDS Epidemic:*** Gay and bisexual men and transgender individuals (especially individuals of color, transgender women, and youth) are at particular risk for HIV/AIDS and other STIs. Thus, the Administration must develop a National AIDS Strategy designed to lower HIV incidence, increase access to HIV/AIDS care, and reduce racial disparities in the epidemic among LGBT populations. It should also integrate HIV/AIDS with prevention and treatment programs for other STIs, viral hepatitis, and TB wherever possible.

For more information or to request a copy of the Principles, please contact Kellan Baker, Policy Associate at the National Coalition for LGBT Health, at (202) 558-6828 or Kellan@lgbthealth.net.

The following organizations have signed on in support of these Principles:

1199 SEIU

A Brave New Day (Mississippi)

AIDS Action

Advocates for Youth

African American Office of Gay Concerns

The AIDS Institute

AIDS Rochester, Inc.

American College of Sexologists

American Medical Student Association

American Psychological Association

The Association of Lesbian, Gay, Bisexual, and Transgender Addiction Professionals and
Their Allies

The Association for Women in Psychology

Boston Alliance of Gay, Lesbian, Bisexual, and Transgender Youth, Inc. (Massachusetts)

Bienestar (California)

Black Women's Health Imperative (Washington, D.C.)

Callen-Lorde Community Health Center (New York)

Cascade AIDS Project (Oregon)

Center for HIV Law and Policy

CenterLink: The Community of LGBT Centers

Chase Brexton Health Services, Inc (Maryland)

Chicago Department of Public Health (Illinois)

Choices Recovery Services (California)

Coalition of Lavender-Americans on Smoking and Health (CLASH)

Children of Lesbians and Gays Everywhere (COLAGE)

Community HIV/AIDS Mobilization Project (CHAMP)

The DC Center: The Washington, D.C. Community Center for Gay, Lesbian, Bisexual,
and Transgender People

Equality California

Fenway Community Health (Massachusetts)

The Fenway Institute (Massachusetts)

The Gay, Lesbian, Bisexual, and Transgender Youth Support Project of Health Care of
Southeastern Massachusetts, Inc.

Gay and Lesbian Medical Association

Gay Men's Health Crisis

The Gay, Lesbian, and Straight Education Network (GLSEN)

Hartford Gay and Lesbian Health Collective (Connecticut)

Human Rights Campaign

INet London Calling Talk Show

Institute for Advanced Study of Human Sexuality

Family Equality Council

John Snow Research & Training Institute, Inc. (Massachusetts)

Los Angeles Gay & Lesbian Center (California)

The Lambda Community Center of Fort Collins (Colorado)
The Lesbian, Gay, Bisexual, and Transgender Community Center (New York)
The LGBT Physician Assistant Caucus of the American Academy of Physician Assistants, Inc
Legacy Community Health Services, Inc (Texas)
The Long Island Lesbian Cancer Initiative (New York)
Mautner Project: The National Lesbian Health Organization
Meefers, LLC -- <http://www.meefers.com>
Metropolitan Community Churches
Nashville CARES (Tennessee)
National Asian Pacific American Women's Forum
National Association of People with AIDS (Washington, D.C.)
National Center for Transgender Equality
The National Gay and Lesbian Task Force
National Latina Institute for Reproductive Health
National LGBT Cancer Network
National Youth Advocacy Coalition (New York)
Oregon Central Coast PFLAG
Partnership Project
Parents, Families and Friends of Lesbians and Gays (PFLAG) National
PFLAG Central Oregon
PFLAG of Josephine County (Grants Pass, Oregon)
PFLAG Oregon State Council
Planned Parenthood of the Southern Finger Lakes (New York)
Out for Health, LGBT Health & Wellness Project (New York)
Positive Opportunities, Inc. (Pennsylvania)
PreventionWorks! (Washington, D.C.)
Rainbow Health Initiative (Minnesota)
SafeGuards LGBT Health Resource Center (Pennsylvania)
Sexuality Information and Education Council of the U.S. (SIECUS)
Society for the Psychological Study of Lesbian, Gay and Bisexual Issues, Division 44 of
the American Psychological Association
Title II Community AIDS National Network
Tororo Forum for People living with HIV/AIDS Networks (TOFPHANET)
TransAdvocacy Coalition
Transgender Law Center
Women's Therapy Center (Pennsylvania)
Woodhull Freedom Foundation

¹ 5 C.F.R. sec. 630.201(b) defines a "family member" of an employee to include the following: spouse, and parents thereof; children, including adopted children and spouses thereof; parents; brothers and sisters, and spouses thereof; and any individual related by blood or affinity whose close association with the employee is the equivalent of a family relationship.

² AMA Resolution 122, available online at <http://www.ama-assn.org/ama1/pub/upload/mm/38/a08resolutions.pdf>