

# **Changing the Game**

What Health Care Reform Means for Gay, Lesbian, Bisexual, and Transgender Americans

Kellan Baker, National Coalition for LGBT Health Jeff Krehely, Center for American Progress

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## Introduction and summary

President Barack Obama moved forcefully to tackle injustice and discrimination against lesbian, gay, bisexual, and transgender Americans by signing into law two bills long championed by LGBT and human rights organizations.\* First is the Matthew Shepard and James Byrd, Jr. Hate Crimes Prevention Act, which expanded the 1969 federal hate crimes law to include crimes motivated by bias against someone's real or perceived sexual orientation or gender identity. Second is the repeal of "Don't Ask, Don't Tell," the military's ban on service by openly gay, lesbian, or bisexual individuals.

But as Dr. Martin Luther King, Jr. reminded us almost fifty years ago, "Of all the forms of inequality, injustice in health care is the most shocking and inhumane." The Affordable Care Act, the health care reform law passed in March 2010, seeks to remedy this injustice by transforming the U.S. health system. The law expands access to health and affordable health care for millions of people in America, including gay and transgender Americans and others who are among our society's most vulnerable.

Thanks to the Affordable Care Act, many gay and transgender Americans who were never able to afford health insurance or health care soon will be able to apply for Medicaid or affordable private coverage in every state. They will not be subject to denials of insurance coverage on the basis of pre-existing conditions or to arbitrary rescission of vital coverage when they become ill. The Affordable Care Act is also key to efforts such as expanding cultural competency in the health care workforce to include LGBT issues, making preventive care available to everyone who needs it, improving data collection to better identify and address health disparities, and recognizing the increasing diversity of America's families.

<sup>\*</sup>This paper uses "LGBT" and "gay and transgender" interchangeably. Both terms refer to the full range of people who identify as gay, lesbian, bisexual, and/or transgender.

Despite these and other benefits for the LGBT community, the impact of the Affordable Care Act on gay and transgender people and their families remains largely unexplored. This report explains how the new health law already affects this community, and how they and their allies can continue to advocate for broad inclusion as the law is fully implemented between now and 2014.

In the pages that follow, we first provide an overview of the need for health care reform, including the health disparities experienced by gay and transgender Americans that the law must address. This is followed by a brief discussion of several provisions of the Affordable Care Act that hold particular promise for improving the health and well-being of the LGBT community. Next, we investigate four major areas where efforts by LGBT advocates and their allies in each state will be key to ensuring that the new health law delivers the largest possible positive results for the LGBT community when the law is fully implemented by 2014. Specifically, these areas are:

- Achieving comprehensive nondiscrimination protections in health insurance exchanges
- Establishing LGBT-inclusive data collection policies
- Recognizing and including LGBT families in all health reform activities
- · Supporting community-based health interventions that are LGBT-inclusive

In each of these four areas we include recommendations for federal officials and state governments. Briefly, those recommendations include:

- Establish comprehensive and LGBT-inclusive nondiscrimination policies and practices in health insurance exchanges
- Improve our knowledge base on LGBT health disparities, by including sexual orientation and gender identity demographic questions in federal health surveys
- Recognize and include gay and transgender families in the new health law, by
  making sure that definitions of family are not solely based upon marriage and
  adoption laws that automatically exclude LGBT families
- Create community-based healthcare interventions that are responsive to the needs of gay and transgender people

We will examine these recommendations in more detail at the end of the paper. But first we discuss why our nation's healthcare system has been badly in need of reform, and the barriers to good, affordable care that LGBT people currently face.

## The state of healthcare in America

The U.S. health system has long been in crisis. The United States is the world's richest country, and it spends 16 percent of its gross domestic product on health care—far more than any other industrialized democracy. Yet at the beginning of the 21st century, our nation's healthcare system is failing millions of people.

By almost any measure, including efficiency, equity of access and outcome, and effectiveness, the U.S. health system consistently ranks well below its developednation peers. In its <u>landmark 2000 study of the health care systems</u> in 191 countries, the World Health Organization awarded the U.S. system 37th place for overall performance, just ahead of Slovenia and Cuba, and 54th place for fairness.

Worse still, health care costs have been outpacing the growth of America's gross domestic product—the sum of our economic output—since 1970, increasingly restricting access to vital health care services to those who can secure adequate insurance coverage or who can afford to pay for expensive treatments out of pocket. In 2007, 50 percent of health care spending in the United States was used to treat just five percent of the population.

Insurance is also becoming harder to obtain. The shortcomings of America's insurance industry include practices such as denying coverage to people with pre-existing conditions such as hypertension, HIV, or a previous cancer diagnosis (known as "cherry picking") and searching for excuses to cancel a sick person's coverage rather than pay for their treatment (known as "lemon dropping"). Such practices have left an estimated 46 million Americans without insurance, in addition to an unknown number of people without citizenship documents. Almost 45,000 people die in America every year because of health complications tied to their lack of insurance coverage.

Without the Affordable Care Act, even people who have insurance have enjoyed no guarantees. Aside from the threat of losing coverage as a result of job loss, divorce, or insurance company discrimination, an increasing number of people in

America are underinsured, meaning that their health insurance does not adequately protect them from high medical expenses. Every year, <u>medical bills bankrupt 700,000 Americans</u>, accounting for over 60 percent of bankruptcies across our nation. Of these people, 75 percent were insured at the time they became ill.

#### What does this have to do with LGBT health?

The shortcomings of the U.S. health system are magnified for marginalized and underserved Americans, including people who are lesbian, gay, bisexual, and transgender. Widespread discrimination in employment, relationship recognition, and health care on the basis of real or perceived sexual orientation or gender identity has caused significant disparities between LGBT people and the general population.

The disparities affecting this community include less access to insurance and health care services, including preventive care such as cancer screenings, and lower overall health status. For example, gay men and lesbians experience elevated rates of certain cancers, including breast cancer, melanoma, and non-Hodgkin's lymphoma, and lesbian and bisexual women are at greater risk than heterosexual women for chronic diseases linked to smoking and obesity.

Approximately 30 percent of gay and transgender youth report having been physically abused by family members because of their sexual orientation or gender identity or expression, and it is estimated that up to 40 percent of homeless youth in the United States identify as gay, lesbian, bisexual, or transgender. Men who have sex with men account for more than 50 percent of the 56,000 new HIV/AIDS infections annually, and HIV/AIDS prevalence among transgender women, particularly transgender women of color, exceeds 25 percent nationwide.

Due in significant part to the burden of minority stress, the LGBT community also faces elevated risk for substance use and mental health conditions such as depression, anxiety, eating disorders, and suicidal ideation.

These health disparities are exacerbated by the fact that gay, lesbian, and bisexual adults are roughly twice as likely as the general population to be without health insurance coverage, and rates of uninsurance are even higher for transgender individuals. Because our nation does not have a public health insurance system and individual coverage is currently prohibitively expensive, most people access insurance through their employers. Yet the continued failure by Congress to pass the

Employment Nondiscrimination Act means that people who are gay or transgender can still be fired for their real or perceived sexual orientation in 29 states, and for their real or perceived gender identity or expression in 38 states.

Because of persistent workplace discrimination and harassment, including being verbally or physically harassed, removed from direct contact with clients and customers, or fired without cause, LGBT people are more likely to lose or quit their jobs, to be employed in lower-wage jobs with no benefits, or to not be hired in the first place. A study by the National Gay and Lesbian Task Force and the National Center for Transgender Equality shows that 97 percent of more than 6,400 transgender respondents had been mistreated at work because of their gender identity or expression.

Another important route to health insurance coverage in the United States is through a spouse's employer. Unfortunately, most U.S. states do not legally recognize the relationships of same-sex couples, and many workplaces do not provide health insurance benefits for the same-sex domestic partners of their employees. Research shows that if all employers offered domestic-partner benefits, the uninsured rates for same-sex and different-sex unmarried couples would decrease by as much as 43 percent.

Further, due to inequities in tax law, an employee with a same-sex partner must pay payroll taxes on the cash value of any domestic partner benefits, which increases the cost of insurance for these couples by an average of \$1,100 per year relative to the costs borne by married heterosexual workers.

Because gay and transgender Americans face numerous barriers to insurance and to timely and appropriate preventive care, they are particularly vulnerable to insurance industry practices that restrict access to coverage on the basis of pre-existing conditions. Conditions such as high blood pressure, diabetes, HIV, or a cancer diagnosis are often used as pretexts to deny coverage, and late diagnosis and treatment lead to a higher prevalence of serious, advanced-stage disease and often to premature death. For transgender people in particular, insurance coverage can be nearly impossible to obtain. Despite statements from entities like the American Medical Association defining transition-related care as medically necessary, many private insurers, Medicaid plans in the majority of states, and Medicare all include explicit "transition exclusions" prohibiting coverage of such care. Transition exclusions are often expanded in practice by insurance carriers and medical providers to prevent transgender people from accessing even basic health care services.

Most relevant federal and state laws do not support family structures that are inclusive of LGBT people, so health disparities and challenges increase exponentially for the children of same-sex parents, older gay and transgender adults, and gay and transgender youth, particularly those who are homeless as a result of family rejection. Many members of the LGBT community also belong to other communities that face discrimination and are thus vulnerable to cumulative negative health consequences. An African-American gay man, for example, faces disparities that affect African Americans as well as those experienced by gay men. And a transgender Spanish-speaking woman in the United States must navigate multiple layers of discrimination based on language, ethnicity, gender, and gender identity.

## How the Affordable Care Act will benefit LGBT Americans

Numerous sources, including Healthy People 2020 and the Institute of Medicine's upcoming report on LGBT health and research (which is called "The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding," and will be released on March 31, 2011), testify to the impact of health disparities on the gay and transgender community and have set the stage for substantial efforts to address these disparities. Between now and 2014, the Affordable Care Act promises comprehensive health system reform that prioritizes prevention and wellness, closes health disparities, and makes health care affordable and accessible for everyone, including gay and transgender people and their families.

Only one provision (Section 5306, regarding participation by people of "different genders and sexual orientations" in mental and behavioral health education and training programs) explicitly mentions the LGBT community, but the law as a whole implicitly recognizes the toll that disparities, discrimination, and inequity are taking on gay and transgender people as part of the fabric of American society.

The following sections provide a brief overview of several ACA provisions that hold particular promise for improving the health and well-being of the LGBT community.

## Accessing affordable and comprehensive health insurance coverage

A key aspect of the Affordable Care Act for the LGBT community is the expansion of health insurance coverage that is affordable, accessible, and comprehensive.

## Expanded insurance coverage

The estimated 46 million uninsured people in the United States include many members of the LGBT community. Because LGBT people and their families are regularly discriminated against in employment, relationship recognition, and

insurance coverage, they are roughly twice as likely as the general population to be uninsured. Thanks to the Affordable Care Act, many previously uninsured LGBT people will soon be able to access vital coverage.

One of the central pillars of the new health law is the so-called "individual mandate," which requires nearly all Americans to enroll in a qualified health insurance plan by 2014. The individual mandate is designed to support universal health coverage by making coverage everyone's responsibility: bringing everyone, including young, healthy people, into the insurance pool makes insurance more affordable by spreading risk and lowering overall costs.

To help people with an annual income between 133 percent and 400 percent of the federal poverty level (about \$14,000 to \$42,000 for a single person) access coverage, the law requires each state to establish a health insurance exchange. Starting in 2014, the exchanges will function as marketplaces where consumers and employers can compare different plans and take advantage of income-based premium subsidies that will keep coverage affordable.

For adults whose income is less than 133 percent of the federal poverty level, the law opens eligibility for Medicaid, the federal program for low-income Americans and their families. Of the 32 million people who are anticipated to gain coverage under the Affordable Care Act, 16 million will be newly covered by private insurance sold largely through the new health exchanges, while the remaining 16 million will be covered by Medicaid. The vast majority of the costs of the Medicaid eligibility expansion will be paid by the federal government rather than the states.

Sections 1311 and 2001 of the new law discuss the expansion of insurance coverage.

### Immediate access to coverage

Because LGBT people face numerous barriers to insurance and to timely and appropriate preventive care, they are vulnerable to predatory insurance industry practices that limit or deny insurance to those who need it most. Beginning in 2014, the Affordable Care Act prohibits these practices and ensures that conditions like high blood pressure, diabetes, HIV, or a cancer diagnosis are not used as pretexts to drop or deny coverage.

To serve as a bridge until this prohibition comes into effect in 2014, the new law creates new pre-existing condition plans that provide an insurance option for those who have previously been denied coverage. On www.healthcare.gov (www. CuidadodeSalud.gov in Spanish), consumers can now "one-stop shop" for insurance coverage options, including pre-existing condition plans and coverage for domestic partners in states that recognize these relationships.

Section 1101 of the new law discusses pre-existing condition plans.

## Comprehensive benefits

Even when gay and transgender people are able to access health insurance, many available plans fail to provide comprehensive coverage. Mental health treatment, appropriate preventive care, sexual health counseling, and other services that are an important part of maintaining health and wellness for gay and transgender people are often not covered. Under the new health reform law, all plans sold through the exchanges must be certified as "qualified health plans," and plans sold outside the exchanges may also seek certification as QHPs. At a minimum, QHPs must cover a specified list of "minimum essential benefits," which include:

- Ambulatory patient services
- Emergency services
- Hospitalization
- Maternity and newborn care
- Mental health and substance use disorder services, including behavioral health treatment
- Prescription drugs
- Rehabilitative and habilitative services and devices
- Laboratory services
- Preventive and wellness services and chronic disease management
- Pediatric services, including oral and vision care.

The Department of Health and Human Services and the Institute of Medicine are currently determining which specific services constitute the federal minimum for these categories of essential benefits, but states may include additional requirements in their QHP certification standards.

Sections 1302 and 1321 of the new law define the categories of essential benefits and the qualified health plan certification standards.

## Patient rights

Patient protections are vital for LGBT people, who encounter numerous barriers in accessing insurance, appropriate health services, and care from providers familiar with the LGBT community. The new Patient's Bill of Rights, which came into effect on September 23, 2010, includes several new protections regarding access to health care services and to insurance benefits. In addition to prohibiting insurers from unfairly canceling coverage on the basis of pre-existing conditions, the Patient's Bill of Rights prohibits annual and lifetime limits on coverage, protects each person's right to choose a doctor, removes insurance barriers to emergency services, and guarantees the right to external review and appeal of any insurance coverage determination.

Section 1001 of the new law outlines the Patient's Bill of Rights.

### Coverage for children and young adults

Same-sex couples live in almost every county across the United States, and more than one million of these couples are raising children. The new law ensures that children can stay on their parents' health insurance through age 26 and prohibits insurers from denying coverage to children on the basis of pre-existing conditions.

Section 1001(5) of the new law discusses health insurance access for children and young adults.

## Improving mental and physical health and wellbeing

The Affordable Care Act will improve mental and physical health and well-being for the LGBT community by prioritizing mental health and substance abuse treatment, targeting health disparities, and investing in prevention and wellness.

#### Prioritizing mental health and substance use treatment

Discrimination, stigma, and family rejection strongly contribute to the disproportionate burden of mental health and substance use issues borne by gay and transgender Americans. The new health law includes mental health and substance use

recovery services among the essential benefits that all qualified insurance plans must offer. The law also expands the accessibility of mental health and substance use services by supporting the integration of these services with primary care services, including in settings such as school-based health centers.

Sections 1302, 1311, 4101, and 5306 of the new law discuss mental health and substance use treatment.

### Targeting health disparities

Gay and transgender people come from all kinds of backgrounds and are part of every racial, ethnic, religious, and socioeconomic group. The challenges of being LGBT in the United States are felt even more strongly by people who must cope with additional sources of discrimination, such as entrenched racism, sexism, stigma associated with HIV/AIDS, and other barriers that limit their access to health care and threaten their ability to keep themselves and their families healthy.

Though it does not specifically mention gay or transgender people, the new health law prioritizes programs, research, and data collection that focus on serving communities of color and other systematically disadvantaged groups. It also creates new Offices of Minority Health and Offices of Women's Health within each of the operating divisions of the federal Department of Health and Human Services. The Women's Health Amendment within the Affordable Care Act requires that all health insurance plans cover a defined package of benefits for women; the list of benefits is currently under development by HHS and the Institute of Medicine.

Sections 3013, 3509, 3511, 4302, 10334 discuss some of the new law's efforts to eliminate health disparities.

### Investing in prevention and wellness

The number of lives lost every year to preventable or controllable conditions like cancer, AIDS, and heart disease powerfully demonstrates the importance of prevention for everyone, including gay and transgender people. Thanks to the Affordable Care Act, a wide range of life-saving preventive services will now be available without out-of-pocket costs through all insurance plans, and Medicare beneficiaries will receive a comprehensive annual wellness visit and a personalized prevention plan. LGBT people in communities around the country will have the opportunity to participate in the Community Transformation Grants program and other wellness and prevention initiatives supported by the \$15 billion Prevention and Public Health Fund. Other prevention and wellness priorities under the new law will be outlined by the National Prevention and Health Promotion Strategy, which will be released in spring 2011.

Sections 2713, 4001, 4002, and 4103 outline the new law's approach to prevention and wellness.

## Prioritizing cultural competency and high-quality care

The Affordable Care Act prioritizes the development of cultural competence standards and training in order to remove barriers to health care services, improve the quality of care, build a strong and diverse health care workforce, and support community health centers. These provisions have huge potential to help LGBT people access health care services that are provided in a culturally competent and more easily accessible manner.

## Removing barriers to health care services

Finances are not the only barrier to health care for the LGBT community: A key indicator of health care access and quality for gay and transgender people is their ability to find health care providers who respond to their individual needs and concerns. Unfortunately, many LGBT people and their families are misunderstood, mistreated, or openly discriminated against by health care providers who are not familiar with or sympathetic to their needs. The Affordable Care Act prioritizes the development of cultural competency standards and training in the health system and recognizes that relationships between patients and providers work best when they are based on mutual communication and trust.

Sections 5301, 5306, and 5307 of the new law discuss cultural competence.

## Improving quality of care

Gay and transgender people often receive substandard care as a result of providers who lack an understanding of LGBT health needs and an increasingly overstretched and fraying health care delivery system. The new health law creates a National Strategy for Quality Improvement, which will address gaps in quality of care for different groups in America and help develop strategies for reducing these disparities. The law also focuses on innovation in health care quality measurement, which can help identify and track LGBT health disparities.

Sections 3011, 3013, 3014, 3015, 3501, and 3508 of the new law cover quality improvement initiatives.

## Building a strong and diverse health workforce

Expanding access to high-quality health care for LGBT people requires building and maintaining a well-trained health workforce. The Affordable Care Act recognizes that a strong health workforce must reflect the diversity of American society and must be trained to meet the needs of all patients, including LGBT people and their families. The new health law invests in comprehensive workforce development strategies, including recruiting and training nurses, doctors, physician assistants, and other professionals who come from diverse personal and professional backgrounds. The law creates a new National Health Care Workforce Commission to make recommendations about national health workforce priorities, including workforce issues affecting special populations. It also supports the expansion of the National Health Service Corps, or NHSC, which places newly trained health professionals in underserved areas and provides loan repayment in exchange for work with underserved populations.

Sections 3501, 3506, 5105, 5102, 5207, and 5403 of the new law discuss workforce development.

## Supporting community health centers

Community health centers are key to many aspects of health reform, particularly those aimed at alleviating shortages of primary care providers, addressing health disparities, and broadening access to culturally competent care for communities

such as the LGBT community. By 2019, community health centers are expected to double their number of patients to nearly 40 million annually, meaning that more than 1 in 10 people nationwide will be receiving care from a center within the next 10 years.

To help community health centers prepare for this anticipated patient surge, the new health law permanently reauthorizes the program over the next five years, allocating an additional \$11 billion in funding over for new and existing centers, and creating new opportunities for the centers to apply for demonstration grant funding for various projects. The Affordable Care Act also creates a negotiated rulemaking process to revise the designations of medically underserved populations, medically underserved areas, and health professionals shortage areas, all of which will affect the eligibility criteria for facilities wishing to receive federal funding as federally qualified health centers.

This process involves substantial efforts to develop eligibility standards and designations that include centers that focus on providing high-quality, culturally competent care to gay and transgender people. The new rules are due to be released in July 2011.

These provisions are found in sections 4206, 5313, 5508(a) and (c), 5601, 5604, 10333, 10503, and 10608 of the new health law.

## Filling knowledge gaps

The Affordable Care Act seeks to fill knowledge gaps in health care by collecting health and health disparities data, as well as supporting new research in fields such as health services delivery. Given the dearth of data on the health status and outcomes of LGBT people, these provisions of the law have great potential to expand our understanding of the particular needs and concerns of the LGBT community.

#### Collecting health and health disparities data

To address health disparities, the new health law requires the collection and reporting of specific disparities-related data in health programs and surveys, and authorizes the secretary of Health and Human Services to identify and require additional disparities-related demographic data to be collected and reported. The statute enumerates race, ethnicity, gender, disability status, and primary language, and HHS is currently engaged in determining whether additional populations such as LGBT people—will also be included under this provision.

This provision is in section 4302 of the new law.

## Supporting new research

The new health law invests in a range of health care delivery and public health research strategies that will enhance knowledge of LGBT health, in conjunction with the upcoming Institute of Medicine report on LGBT health and research gaps. The Affordable Care Act supports research in health care delivery system reform through investment in the new Center for Medicare and Medicaid Innovation, which will be important for LGBT people who will gain coverage under the expansion of Medicaid or who are receiving Medicare. The law also establishes the Patient-Centered Outcomes Research Institute to support comparative clinical effectiveness research, and it dedicates new funding for establishing Centers of Excellence like the existing Center of Excellence in Transgender Health at the University of California at San Francisco.

These provisions are in sections 4301, 5401, and 6301 of the new law.

## High-impact areas for LGBT health advocacy

The Affordable Care Act seeks to make health insurance more affordable for all Americans and to improve the U.S. healthcare system by expanding access to preventive care and building educational and training resources that meet the needs of all patients. Because LGBT people face barriers to health insurance and evidence-based, culturally competent care, the new law has much potential to benefit this community. Unfortunately, the law does not make explicit calls for LGBT-specific programs, care, and services. But with strategic advocacy efforts in the next year or two, the law's implementation can be crafted to maximize its positive impact on LGBT people.

In this section we investigate four areas in which efforts by gay and transgender advocates and their allies in individual states, working in tandem with the federal and state governments, will be key to ensuring that the new health law delivers positive outcomes for the LGBT community. Specifically, gay and transgender advocates and their allies must engage with federal and state entities around LGBT-inclusive initiatives such as:

- Achieving comprehensive nondiscrimination protections in health insurance exchanges
- Establishing LGBT-inclusive data collection policies
- Recognizing and including LGBT families in all health reform activities
- Supporting community-based health interventions that are LGBT-inclusive

Progress cannot happen without LGBT community investment and involvement. In the concluding section of this paper we will detail what needs to be done in these four areas of action.

## Achieving comprehensive nondiscrimination in health insurance exchanges

One of the most vital aspects of the new health law is the expansion of insurance coverage to those who were previously uninsured. The estimated 46 million uninsured Americans in the United States includes many gay and transgender people: Discrimination against these groups in employment, relationship recognition, and insurance often results in a cycle of uninsurance, unmet medical needs, and spiraling costs, especially for late-stage care.

The unusually tumultuous process of drafting and passing the Affordable Care Act resulted in several key concepts being incompletely incorporated into the final bill. Chief among these is comprehensive nondiscrimination. The legislative history of the various bills in the House and the Senate clearly demonstrates that many lawmakers envisioned protecting all health care consumers "without regard to personal characteristics extraneous to the provision of high quality health care or related services," including sexual orientation and gender identity.

The process of setting up the health insurance exchanges in the period between 2010 and 2014 affords the federal government and the states a crucial opportunity to remedy this void in the final law by creating regulations that support the goal of expanding insurance coverage, particularly for groups that have historically faced discrimination and marginalization. Coordinated initiatives by Department of Health and Human Services, the federal Office of Personnel Management, and the states around the establishment and operation of the state health insurance exchanges will be key to developing regulatory nondiscrimination policies that are inclusive of sexual orientation and gender identity.

## What can the Department of Health and Human Services do?

Section 1321 of the law requires the secretary of HHS to "provide for the efficient and nondiscriminatory administration of exchange activities," and states that "the Secretary shall ... issue regulations setting standards for meeting the requirements of this title ... with respect to the establishment and operation of exchanges ... the offering of qualified plans ... and other such requirements as the Secretary determines appropriate." To achieve the degree of nondiscrimination protections necessary for truly expanding the accessibility of health insurance, the secretary should work with the new Center for Consumer Information and Insurance

Oversight, housed at the Centers for Medicare and Medicaid Services, and the HHS Office of Civil Rights to promulgate federal guidance for the operation of state health insurance exchanges and the certification of qualified health plans.

This guidance should include explicit antidiscrimination protections regarding gender identity and sexual orientation in all aspects of insurance. These aspects include marketing, purchase, enrollment, rating and underwriting, covered benefits, premiums, cost sharing, taxation, and privacy standards. Additionally, HHS should make clear that state-run exchanges must abide by all applicable state nondiscrimination, consumer protection, and human rights laws, some of which already include sexual orientation and gender identity as protected classes.

## What can the Office of Personnel Management do?

Section 1334 of the Affordable Care Act requires OPM to enter into contracts with insurers to offer at least two multistate qualified health plans through each state's health insurance exchange. Each multistate qualified health plan must be licensed by the respective states in which it plans to operate, and at least one of the multistate plans must be run by a nonprofit corporation. To ensure that gay and transgender Americans have equal access to multistate plans, the director of OPM should issue regulations and guidance for these plans that prohibit discrimination on the basis of sexual orientation and gender identity.

#### What can states do?

State governments are largely in charge of the design, implementation, and operation of the new health insurance exchanges, including the establishment of certification requirements for qualified health plans that meet or exceed those established by HHS. To ensure that coverage through the exchanges is accessible to LGBT people, states should establish certification requirements for qualified health plans that prohibit discrimination on the basis of factors such as gender identity or sexual orientation. Several key components of such certification requirements are outlined below:

#### Do not discriminate in coverage decisions

Coverage determinations should be made without prejudice on the basis of factors such as the gender, gender identity, sexual orientation, or sexual behavior of the patient receiving the service. Some health services, such as gynecological exams

and certain cancer screenings, are traditionally "gendered," meaning that health insurers routinely refuse to cover these services for anyone whose gender marker on their insurance documents does not match their physical anatomy. State regulations governing the exchanges should ensure that such decisions about appropriate screenings and other care are made by patients and providers, not insurance companies. All services should be offered strictly on the basis of whether they are required to regain or maintain health.

Moreover, if a state requires services such as hormone replacement therapy, fertility services, or cancer screenings to be covered by all plans sold through the exchanges, such services should be covered for all patients for whom they are medically necessary, regardless of gender, gender identity, sexual orientation, or relationship status.

#### Protect consumers in Basic Health Plans

If they so choose, states under the new health law may create basic health plans for people with incomes between 133 percent and 200 percent of the federal poverty level, which makes them ineligible for coverage through Medicaid and most likely unable to easily afford coverage through the exchanges. Basic health plans must offer adequate protections and guarantees to equitable access to health care coverage for all consumers.

These protections will be especially important to gay and transgender people, who experience poverty at disproportionately high rates. To ensure that all consumers who are income-eligible to enroll are afforded equal treatment, any regulations and guidelines for Basic Health Plans should include a nondiscrimination mandate covering sexual orientation and gender identity.

#### Ensure that exchange enrollment is accessible to people from varying backgrounds

Because of the diversity of individuals and small businesses utilizing the exchanges to purchase insurance beginning in 2104, enrollment procedures must be accessible and relevant to all consumers. Enrollment materials, for example, should fully and clearly inform consumers of their rights to nondiscrimination in accessing and receiving insurance. These materials should not assume the race, ethnicity, age, religion, sex, sexual orientation, gender identity, relationship status, or health status of individuals seeking information about exchange plans. Furthermore, insurance plans participating in exchanges should be required to meet these nondiscrimination guidelines in all communications and materials as a prerequisite for eligibility to sell plans in the exchanges.

#### Ensure that navigator programs adequately support choice for LGBT consumers

Navigator programs, which are designed to help consumers assess their insurance options and purchase coverage through the exchanges, should be adequately prepared to serve all potential consumers. A particular focus should be placed on reaching groups that are historically uninsured and underserved, including the LGBT community. As such, navigator programs should be required to include nondiscrimination guarantees that ensure equal service to all consumers, regardless of factors such as sexual orientation or gender identity.

To ensure informed choice among plans offered through the exchanges, navigator programs should include access to plan information that is relevant and helpful to a broad range of consumers, including adequate information on coverage of services relevant to LGBT consumers, such as appropriate reproductive health services, medically necessary care for transgender people, and coverage for conditions such as HIV/AIDS. Finally, to ensure that the maximum number of people is aware of their insurance options and given adequate guidance in enrollment, all outreach conducted by navigator programs should include gay and transgender consumers. This outreach may include using LGBT-inclusive images and language, as well as advertising in publications and media targeting these consumers.

## Ensure that innovation dollars reach the LGBT community

The Department of Health and Human Services has awarded several rounds of grants to the states to fund innovation and advances in the design and implementation of the exchanges. In February 2011, for example, seven states (Kentucky, Maryland, Massachusetts, New York, Oklahoma, Wisconsin, and Oregon) received "early innovator" awards to help them develop the health information technology infrastructure needed to operate the exchanges. State departments of health and other exchange-related entities in these and other states should ensure that their efforts include the needs of the LGBT community. In the case of health insurance technology, this involves developing data fields for electronic medical records that allow providers to input sexual orientation and gender identity data.

## Counting gay and transgender Americans

A lack of standardized data collection on sexual orientation and gender identity severely hampers both government and community-based efforts to identify, track, and address health disparities among LGBT people. As Healthy People 2020, the federal blueprint of a healthier nation over the decade from 2010 to

2020, notes, "Sexual orientation and gender identity questions are not asked on most national or State surveys, making it difficult to estimate the number of LGBT individuals and their health needs."

The "Strategic Plan on Addressing Health Disparities Related to Sexual Orientation," released by HHS in April 2001, stated bluntly that "Unless SO/GI [sexual orientation and gender identity] health concerns are included broadly in Departmentsponsored health surveys, research, and surveillance systems, it will not be possible to document, understand, or address health disparities in this population."

A recent Center for American Progress publication, "The Power of the President: Recommendations to Advance Progressive Change," echoes these concerns and further notes that, "In the absence of accurate data, policymakers are often unable to assess the effectiveness of current policies in meeting the needs of lesbian, gay, bisexual, and transgender people... [and] the lack of good data in policy debates and decisions increases the likelihood that stereotypes and myths will guide policies that impact LGBT Americans." Likewise, professional bodies such as the American Medical Association, the American Public Health Association, and the American Psychological Association have issued statements in support of standardized data collection on sexual orientation and gender identity.

Recognizing the need to close the gap in data on gay and transgender Americans, Section 3171 of H.R. 3962, the health care reform bill passed by the House of Representatives, specifically directed HHS to collect data on sexual orientation and gender identity, among other disparity factors.

## What can the Department of Health and Human Services do?

Section 4302 of the Affordable Care Act requires HHS to collect data on gender, race, ethnicity, disability status, and primary language in order to identify, track, and address disparities related to these factors. Section 4302 also allows the secretary of HHS to designate additional groups that experience health disparities and would benefit from improved data collection. To begin to truly investigate and combat the health disparities facing the LGBT population, the secretary should include sexual orientation and gender identity data collection under Section 4302.

#### What can states do?

Many states, including North Dakota, Massachusetts, California, Wisconsin, North Carolina, and New Mexico, recognize the challenges posed by a lack of health and demographic data on LGBT people and have added questions on sexual orientation and/or gender identity to their Behavioral Risk Factor Surveillance Systems, which are the source of most health and health disparities data for the states. Numerous studies used this state-level data to create a more complete picture of the health disparities affecting the LGBT community. Since decisions regarding adding questions to the BRFSS questionnaires are made by each state, individual states should commit to investigating health disparities related to sexual orientation and gender identity in their BRFSS questionnaires.

## Recognizing and including LGBT families in the new health law

American family structures are increasingly varied. According to recent data from the U.S. Census, we are a nation of blended, multigenerational, and multinational households, adoptive and foster families, and families headed by single parents, divorced parents, unmarried parents, and same-sex parents. Data from the 2010 Current Population Survey, for example, reported 7.5 million couples living together who were not married, and an estimated 620,000 of these households were headed by same-sex couples.

Other research by the Williams Institute indicates that approximately 2 million American children under the age of 18 are being raised by parents in same-sex relationships. Yet only a small number of these families are protected by law, and these protections are tenuous at best. Due to the lack of consistent relationship recognition for same-sex couples across jurisdictions in the United States, a couple that is legally married in one state may be considered legal strangers in another.

All families, regardless of formal structure or composition, need assistance with their responsibility for keeping all of their members safe and healthy. The new health law includes numerous references to family, child, spouse, parent, dependent, and other terms meant to connote familial relationships. How these terms are defined will determine who has access to the new benefits and programs created by the law, including:

- Insurance market protections
- Premium assistance
- Family-provided home- and community-based services
- Family caregiver support services
- Other programs established by the new law for which eligibility is linked to family relationships

For the Affordable Care Act to achieve its goals of promoting health and providing access to affordable health care for everyone, federal and state regulations must recognize that family is a matter of function, not form, and must take steps to avert discrimination on the basis of family composition or marital status.

## What can the Department of Health and Human Services do?

The secretary of HHS should issue rules ensuring that, to the extent permitted by law, the full diversity of families in the United States, including LGBT-headed families, are eligible for new benefits and programs created by the new health law. This includes respecting but not pre-empting state definitions of family, child, spouse, parent, dependent, and other terms meant to connote a familial relationship that are more inclusive than any federal definition.

Examples of inclusive definitions of family include the Office of Personnel Management's sick-leave regulations. Under the OPM rules, a "family member" includes domestic partners and "any individual related by blood or affinity whose close association with the employee is the equivalent of a family relationship." In addition, President Obama's June 2010 memorandum extending certain employee benefits to the partners and children of LGBT federal employees used definitions of "child" and "family member" that are inclusive of the partners and children of LGBT individuals.

The Joint Commission, an independent nonprofit organization that certifies more than 18,000 health care programs and accredits more than 95 percent of hospital beds in the United States, defines "family" as "any individual that plays a significant role in the patient's life, such as spouses, domestic partners, significant others (of both different-sex and same-sex), and other individuals not legally related to the patient." This is the standard that should be applied to LGBT-headed families whenever possible under federal and state law.

#### What can states do?

Similarly, each state should develop regulations for the exchanges and other programs established by the Affordable Care Act that protect and promote access for members of all kinds of families to health insurance and high-quality, affordable health care. State governments, for example, should offer domestic partner benefits for their employees, as a way to model best practices for private employers. Further, states should require insurance plans sold through their exchanges to offer domestic partner benefits if they also offer spousal benefits.

## Supporting community-based interventions that work for LGBT people

The new health law includes numerous provisions intended to promote community-based public health initiatives. In particular, the \$15 billion Prevention and Public Health Fund will fund initiatives such as the Community Transformation Grants. These grants are intended to support broad community-based strategies to eliminate health disparities and foster healthier and more resilient communities by targeting resources to underserved communities and ensuring participation of diverse community stakeholders in the process of implementing reform and shaping the nation's prevention and wellness agenda.

## What can the Department of Health and Human Services do?

The effectiveness of programs such as the Community Transformation Grants in offering new opportunities for the LGBT community to help improve the health and well-being of its members hinges on the definition of "community." The Centers for Disease Control and Prevention should recognize that, like health disparities, communities are not always confined by zip codes. In order to effectively promote positive outcomes for groups of Americans facing health disparities, the definition of "community" must be expanded beyond physical boundaries toward an understanding of communities shaped by shared identities and common health disparities.

Interventions focusing on such communities can have positive risk-reduction effects in multiple local areas, and can help to build the evidence needed to replicate proven approaches to fighting health disparities facing communities as diverse as the LGBT community, communities of color, non-English-speaking communities, and others. Interventions focused on shared-identity communities can also have spillover effects: By contributing to broader structural changes that improve health and reduce risk in local areas, interventions such as antistigma campaigns, strong antibullying laws, and dedicated investments in preventive and primary care for certain groups of Americans can help foster a safer, healthier climate for everyone.

#### What can states do?

Existing programs such as the Pioneering Healthy Communities initiative, created by the YMCA and funded by the federal Center for Disease Control and Prevention, demonstrate that the best partners for community-focused initiatives are most often organizations with deep roots in local communities. This fosters the cultural competency, mutual trust, and accountability necessary to implement effective prevention and wellness interventions, particularly in communities that have experienced persistent disadvantages and discrimination. When choosing partners and advisers for designing and implementing projects under programs such as the Community Transformation Grants, state governments and their departments of health should proactively seek to partner with members of disparity communities, including the LGBT community.

A critical aspect of reaching these communities is inclusive language in outreach materials and in documents such as requests for proposals, or RFPs, and requests for applications, or RFAs. In particular, any RFP or RFA released by a state department of health or other entity regarding community-oriented funding initiatives under the new health law should include a specific mention of groups of Americans experiencing health disparities that explicitly includes the LGBT community.

## Conclusion

Before comprehensive health care reform became the law of the land, too many lesbian, gay, bisexual and transgender people were destined to remain uninsured and unable to afford regular checkups and basic medical care. Too many in the LGBT community faced the prospect of continuing to go to bed at night worrying about paying their health care bills, and too many gay and transgender parents envisioned a future where they would continue to be unable to afford to take their children to the doctor. Passage of the Affordable Care Act changed all of that.

Implementation of the Affordable Care Act is a historic opportunity for transforming our health system, prioritizing prevention and wellness, and making health care affordable and accessible for everyone. In order for the aspirations of the law to be fully realized, however, the federal government and the states must explicitly ensure that gay and transgender Americans and their families are fully covered under the new law. The LGBT community and its allies must take action to move successful implementation forward and to defend the law from efforts to defund or otherwise dismantle it.

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The Center for American Progress is a nonpartisan research and educational institute dedicated to promoting a strong, just and free America that ensures opportunity for all. We believe that Americans are bound together by a common commitment to these values and we aspire to ensure that our national policies reflect these values. We work to find progressive and pragmatic solutions to significant domestic and international problems and develop policy proposals that foster a government that is "of the people, by the people, and for the people."

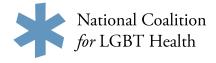
#### **About the National Coalition for LGBT Health**

The Coalition is committed to improving the health and well-being of lesbian, gay, bisexual, and transgender individuals through federal advocacy that is focused on research, policy, education, and training.

The LGBT community includes individuals of every sexual orientation, gender, gender identity, race, ethnicity, and age; regardless of disability, income, education, and geography. Our members are dedicated to effecting change by uniting this rich diversity at the national level.



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