

Essential Elements of a Revised National Health Care Policy for LGBT People and People Living with HIV

By Tim Wang and Sean Cahill

Executive Summary

The 2010 Patient Protection and Affordable Care Act (ACA) resulted in 20 million Americans gaining access to health insurance who were previously unable to obtain it due to pre-existing conditions or because they could not afford it.¹ This increase in coverage has significantly benefited groups that experienced lower rates of health insurance coverage, such as lesbian, gay, bisexual, and transgender (LGBT) people, people living with HIV (PLWH), and Black and Latino people. Prior to implementation of the Affordable Care Act (ACA), studies showed that 22% of Black adults and 33% of Latino adults were uninsured, compared with just 14% of White non-Hispanic adults.² The Kaiser Family Foundation estimates that uninsurance rates declined among Latino nonelderly individuals from 30% in 2013 to 21% in 2015. Among Blacks the uninsurance rate declined from 19% in 2013 to 11% in 2015. Among Asian Americans the uninsurance rate was cut in half, from 14% to 7%, and among White non-Hispanic individuals the uninsurance rate declined from 12% in 2013 to 7% in 2015.³

The 20 million newly insured Americans are disproportionately Black and Latino, LGBT, or people living with HIV or other chronic diseases.

In 2013, before key provisions to expand access to health insurance were implemented, just 17% of the estimated 1.2 million Americans living with HIV had private health insurance.⁴ The U.S. Centers for Disease Control and Prevention and the Kaiser Family Foundation estimate that the percentage of people living with HIV who lacked any kind of health insurance coverage was 22% in 2012 and dropped to 15% in 2014, following implementation of key elements of health care reform. The percentage of PLWH on Medicaid increased from 36% in 2012 to 42% in 2014.⁵ The ACA, and Medicaid expansion in particular, have been very important to covering the health care costs and needs of PLWH.

A 2014 Gallup study found that LGBT Americans were more likely to report being uninsured than non-LGBT Americans.⁶ Between June/September 2013 and December 2014/March 2015, however, the percentage of LGB adults without health insurance decreased from 21.7% to 11.1%, which is a larger decrease than in the non-LGB adult population⁷.

Black and Latino people, LGBT people, and PLWH are also disproportionately affected by health disparities and experience increased barriers to health care access. For example, compared to heterosexual individuals, LGB individuals report higher rates and earlier onset of disability;⁸ lesbian and bisexual women are less likely to receive preventive cancer screenings;⁹ and gay and bisexual men represent two-thirds of new HIV infections in the United States, with Black and Latino men who have sex with men (MSM) experiencing the highest HIV burden among all sub-populations.¹⁰ Transgender people, especially transgender women of color, are disproportionately burdened by high rates of HIV and other STIs,¹¹ as well as high prevalence of victimization and mental health issues, including suicidality.¹² LGBT people are also disproportionately affected by risk factors that contribute to poorer health outcomes, such as poverty,¹³ homelessness,¹⁴ and substance abuse.¹⁵ Members of racial and ethnic minority groups experience a myriad of health disparities at the patient, provider, and system level.¹⁶

LGBT people experience widespread discrimination in health care, which can act as a barrier to seeking routine and emergency medical care.¹⁷ In recent years the federal government took critical steps towards reducing the health disparities experienced by this population. President Trump has promised in the past to keep Medicare, Medicaid, and Social Security without cuts,¹⁸ and he has also stated that he wants to keep protections for people with preexisting conditions.¹⁹ With Congress and the Trump-Pence Administration currently revising U.S. health policy, we hope that these promises will be kept. Regardless, there are a few key elements of the current health policy that are essential to the health and well-being of LGBT people and PLWH that should be retained in any revision of health care reform that is adopted. These provisions include:

- Requiring insurance coverage for those with preexisting conditions and eliminating annual and lifetime spending caps.
- Expanding eligibility criteria for Medicaid and other measures to increase health insurance coverage and health care utilization.
- Prohibiting anti-LGBT discrimination in health care.
- Encouraging sexual orientation and gender identity data collection in clinical settings.
- Encouraging cultural competency training.

Insurance Coverage for Preexisting Conditions and Ending Spending Caps

There are several provisions of the ACA that have increased access to health insurance for LGBT people and PLWH. One of the most important provisions of the ACA for LGBT people and PLWH is the requirement that insurance companies provide insurance to everyone who applies at comparable rates, regardless of preexisting conditions such as HIV infection.²⁰ Only 56.5% of PLWH in 2013 were retained in care, and only 54.7% were virally

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suppressed.²¹ Retention in care is extremely important for PLWH to attain viral suppression, which is vital for both their own health and well-being as well as the prevention of transmission of HIV. Requiring health insurance providers to cover those with preexisting conditions like HIV at comparable rates to everyone else is essential for expanding insurance coverage and health care access for PLWH and other people living with chronic conditions. The ACA also put an end to lifetime or annual spending caps for insurance coverage, which is especially helpful for those with chronic preexisting health conditions like HIV, which require consistent medical treatment throughout an individual's lifetime.

Medicaid Expansion

The ACA also expanded coverage of LGBT people and PLWH by expanding eligibility criteria for Medicaid, which is a health insurance program for low-income children, pregnant women, parents, seniors, and people with disabilities. States currently have the option to expand Medicaid eligibility so that individuals earning up to 138% of the federal poverty level (FPL) qualify for Medicaid health insurance based on income alone.²² The Center for American Progress found that in states expanding Medicaid, 386,500 uninsured low-income LGBT people would be able to qualify for coverage.²³

Prior to 2014, and in states where Medicaid eligibility still has not been expanded, an individual must either be extremely poor with dependent children or be disabled to qualify for Medicaid. For PLWH, being disabled meant having an AIDS diagnosis. This severely limited access to Medicaid for poor LGBT people and PLWH who are not pregnant and do not have dependent children or a disability. This disproportionately affects Black Americans living with HIV, who are overrepresented in states where Medicaid eligibility has not expanded. This includes nearly all of the Southern states. In order to reduce the health disparities that these populations experience, the expansion of Medicaid must be maintained, as well as adopted by the 19 states that have not yet expanded it. It will be essential to maintain these provisions which have successfully increased health insurance access for these vulnerable populations.

Essential Health Benefits

There are other key elements of health care reform that help to expand health insurance coverage and health care access, which is important for reducing the health disparities experienced by LGBT people and PLWH. For example, the ACA guarantees access to essential health benefits, which includes preventive services like HIV/STI screening, prescription drugs, and mental health and substance use treatment. This is especially important for LGBT people because behavioral health issues such as depression and substance use disproportionately burden the LGBT population. For example, studies have shown higher rates of mental health burden, including depression, anxiety, and suicidality in LGB people compared to heterosexual people.²⁴ Studies have also shown that the LGBT population experiences high rates of tobacco,²⁵ alcohol,²⁶ and other substance use.²⁷ Guaranteed access to mental health and substance use treatment can help to reduce these disparities. Such access is also important to people living with HIV, who also experience disproportionate behavioral health burden.²⁸

Nondiscrimination Provisions

Other important provisions that should be maintained are the nondiscrimination provisions included in executive orders and ACA implementation regulations issued from 2010 to 2016. Studies have shown that LGBT people experience widespread discrimination in health care.²⁹ Having a past experience of discrimination in health care or anticipating discriminatory treatment in the future acts as a barrier to seeking routine and emergency medical care.³⁰ A 2012 federal regulation prohibits discrimination on the basis of sexual orientation and gender identity in qualified health insurance plans traded on insurance marketplaces. The regulation also includes language which could potentially protect PLWH from insurance discrimination.³¹ The final rule implementing Section 1557, the nondiscrimination provision of the ACA, prohibits discrimination on the basis of gender identity in health care facilities and programs receiving federal funding, and by insurance policies offered on the federal or state insurance marketplaces. The May 2016 rule also prohibits discrimination in health care against gender nonconforming and non-binary people. The rule implementing Section 1557 prohibits insurance companies from imposing blanket exclusions on gender affirmation treatments. It does not, however, create an affirmative right to insurance coverage of such treatments. The rule also states that covered entities cannot deny treatment to a transgender individual that is offered to a non-transgender individual. For example, if cisgender (i.e. non-transgender) men are offered prostate screening, transgender women—who also have a prostate gland—should be offered the screening and have it covered by insurance as well.

The Section 1557 rule is less explicit in regards to sexual orientation discrimination, but it does state that discrimination based on sex stereotyping is prohibited in health care programs and facilities receiving federal funding. There have been a number of Equal Employment Opportunity Commission (EEOC) rulings³² that have determined that some anti-gay discrimination constitutes sex stereotyping. For example, this could include a lesbian couple that is denied fertility assistance based on the stereotypical belief that women should only date or marry men. On December 31, 2016, Judge Reed O'Connor from the United States District Court of the Northern District of Texas issued a nationwide injunction prohibiting the Department of Health and Human Services from enforcing the Section 1557 rule.³³ The Trump-Pence Administration has not challenged this injunction. Sexual orientation and gender identity nondiscrimination provisions covering health care are essential to ensuring that LGBT people have equal access to high quality and culturally competent health care. Such provisions need to be maintained in some form and enforced nationwide in order to reduce LGBT health disparities.

Sexual Orientation and Gender Identity Data Collection

In recent years the federal government has increased data collection on sexual orientation and gender identity (SOGI). Asking about sexual orientation and gender identity is important because there are wide gaps in research on LGBT health. Gathering these data in a standardized way can help track health outcomes in the LGBT population, and help to inform interventions to reduce LGBT health disparities.

Research has shown that patients are willing to answer these questions and understand the importance of their health care providers knowing their sexual orientation and gender identity.³⁴

Gathering SOGI data in clinical settings is recommended by Healthy People 2020,³⁵ the Institute of Medicine,³⁶ and the Joint Commission³⁷ in order to understand, target, and reduce LGBT health disparities. Several federal regulatory developments also support the collection of SOGI data in clinical settings. Stage 3 Meaningful Use guidelines require that SOGI data fields be incorporated into EHR software in order to be certified under the Meaningful Use incentive program,³⁸ now part of the Medicare Access and CHIP Reauthorization Act (MACRA).³⁹ The Health Resources and Services Administration requires reporting of SOGI data in its Uniform Data Set.⁴⁰ A number of federal surveys are now collecting this data as well. Eleven federal surveys and one study currently ask about sexual orientation, six surveys ask about both sexual orientation and gender identity, and more are currently testing questions.⁴¹ It is essential to our understanding of population health and LGBT health disparities to continue these important data collection initiatives.

LGBT Cultural Competency

More and more health care providers and medical associations are becoming aware of LGBT health disparities and anti-LGBT discrimination in clinical settings.^{42,43} The training of health care providers and those studying to serve as health care providers in standards of health care for LGBT people is key to ensuring clinically and culturally competent⁴⁴ care for LGBT patients.⁴⁵ Cultural competency training helps reduce health disparities by developing provider proficiency in understanding the unique issues LGBT people face.⁴⁶ LGBT people are increasingly included in diversity trainings as an important population whose needs warrant cultural competency training of health care providers, providers working with older adults, and others.⁴⁷ The Joint Commission called for LGBT cultural competency training of health care providers in 2011.⁴⁸ In 2014, the American Association of Medical Colleges released *Implementing Curricular and Institutional Climate Changes to Improve Health Care for Individuals Who Are LGBT, Gender Nonconforming, or Born with DSD: A Resource for Medical Educators*.⁴⁹ In 2015, the American College of Physicians published the second edition of *The Fenway Guide to Lesbian, Gay, Bisexual and Transgender Health*, a medical reference textbook for providers treating LGBT patients.⁵⁰ Increased cultural competency training and education of the current and future health care workforce can reduce the anti-LGBT discrimination that acts as a barrier to receiving health care for this population. It will be important to maintain support for cultural competency training in LGBT health moving forward.

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Conclusion

The ACA contains many provisions that benefit vulnerable populations experiencing disparities in health outcomes and access to health care. This includes LGBT people and PLWH. In order to reduce these disparities, it is essential that the plan for health care reform currently being proposed by the Trump-Pence Administration and Congress retain several key provisions. These include insurance coverage for those with preexisting conditions, elimination of annual and lifetime spending caps, Medicaid eligibility expansion, coverage for essential health benefits, sexual orientation and gender identity nondiscrimination provisions, sexual orientation and gender identity data collection, and LGBT cultural competency in health care.

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