August 13, 2019

U.S. Department of Health and Human Services
Herbert H. Humphrey Building, Room 509F
200 Independence Avenue SW
Washington, DC 20201

RE: Docket ID HHS-OCR-2019-0007, RIN 0945-AA11, Nondiscrimination in Health and Health Education Programs or Activities

I am pleased to submit the following comments on behalf of the Guttmacher Institute in response to a proposed rule by the Department of Health and Human Services (HHS) and the Centers for Medicare and Medicaid Services (CMS), entitled “Nondiscrimination in Health and Health Education Programs or Activities,” published in the Federal Register on June 14, 2019.

The Guttmacher Institute is a nonprofit, nonpartisan research and policy organization committed to advancing sexual and reproductive health and rights in the United States and globally. The Institute’s overarching goal is to ensure high-quality sexual and reproductive health for all people worldwide by conducting research according to the highest standards of methodological rigor and promoting evidence-based policies. The information and analysis it generates on reproductive health and rights issues are widely used and cited by researchers, policymakers, media and advocates across the ideological spectrum.

The proposed rule is an attempt by the Trump administration to undermine the nondiscrimination protections of Section 1557 of the Affordable Care Act (ACA). Section 1557 was designed by Congress to protect people against discrimination on the basis of race, color, national origin, sex, age and disability, and applies to health programs and activities receiving federal financial assistance, programs and activities administered by a federal executive agency, and entities established under Title I of the ACA, such as federal and state health insurance marketplaces.

The provision itself took effect immediately upon the ACA’s enactment in 2010, and the Obama administration issued a final rule in 2016 to help interpret and enforce it. Social conservatives took aim at several parts of the final rule, most notably its explicit protections for people on the basis of gender identity and termination of pregnancy. In December 2016, Judge Reed O’Connor of the Northern District of Texas issued a nationwide injunction prohibiting HHS from enforcing those specific parts of the rule. Despite this injunction against a portion of the rule, Section 1557 itself—the legal protection established by Congress—remains in effect. Moreover, several other federal judges have found that the law itself, regardless of whether HHS has a rule in place, prohibits discrimination on the basis of gender identity.
The proposed rule would roll back numerous parts of the 2016 final rule and narrow its scope and enforcement. Among other things, it would:

- eliminate most of the current rule’s definitions, including its definition of discrimination on the basis of sex, thereby undermining protections for LGBTQ patients and for people on the basis of their reproductive health decisions;
- pull in abortion- and religion-related exemptions from a separate federal sex discrimination law (Title IX, which governs sex discrimination in education), and assert the primacy of federal refusal clauses over the Section 1557 nondiscrimination protections;
- weaken the current rule’s standards to protect people with limited English proficiency;
- narrow the entities covered by the law, such as by asserting that health insurance companies and health plans are largely exempt;
- remove protections around discriminatory marketing and benefit design, endangering care for HIV-positive patients and many others;
- eliminate the current rule’s notice requirements, making it more difficult for patients and enrollees to learn about and exercise their rights; and
- eliminate many of the current rule’s enforcement procedures, including by going back on HHS’s conclusion that patients and enrollees can sue under the law.

All of these changes pose significant risks to those Section 1557 is intended to protect and who often face serious barriers to care, including LGBTQ people, people who need reproductive health care, people of color, people living with disabilities or chronic conditions, and people whose primary language is not English. The proposed changes could add to these barriers, encourage and facilitate discrimination and potentially lead to worse health outcomes. For these reasons, as detailed below, the proposed rule should not be finalized.

Undermining Protections Against Sex Discrimination

The ACA included multiple provisions that recognized long-standing inequities in how the U.S. health system treated patients and enrollees on the basis of sex. For example, it eliminated the common practice of gender rating, under which women were charged higher premiums than men; required coverage of maternity care, which was typically either excluded entirely under individual-market health plans or available only through an expensive rider; and required coverage without out-of-pocket costs for recommended preventive services for women, including contraceptive services and supplies, breastfeeding services and supplies, and other care that insurance plans had often ignored.

Section 1557 of the ACA was designed, in part, as another means of addressing these inequities by explicitly prohibiting sex discrimination in the U.S. health system. The 2016 final rule defined key terms in line with earlier court decisions, such as by making it clear that sex discrimination includes discrimination on the basis of gender identity, sex stereotyping, pregnancy, childbirth and abortion.

Eliminating key definitions

The proposed rule attempts to undermine these protections by eliminating key definitions from the 2016 final rule and by casting doubt on whether the Trump administration will appropriately enforce Section 1557’s protections against discrimination. Combined with other proposed changes to the rule around scope, notice and enforcement (as detailed below), these actions could make it considerably more difficult for people to understand and exercise their right under Section 1557 to be protected against sex discrimination, and could encourage health plans and providers to engage in illegal discrimination.
For example, transgender and gender nonbinary people could be denied coverage or care in cases where a plan or provider restricts a specific service by sex. Many of the most likely examples involve reproductive health care, including care around contraception, abortion, pregnancy and childbirth, infertility, cervical or breast cancer, breast feeding, and sexually transmitted infections. Moreover, transgender and gender nonbinary people could be denied coverage or care for health services related to gender transition. Or they could face discrimination more broadly, such as being denied services entirely or facing discriminatory reception or harassment by companies and staff. In fact, the 2016 final rule explicitly bans several of these practices in provisions that the proposed rule would inappropriately eliminate.

Similarly, any person seeking reproductive health services could face additional barriers and discriminatory treatment as a result of this proposed rule. Section 1557 was designed in part to help ensure that people do not face discrimination in the U.S. health system for their reproductive health needs or decisions, including decisions around abortion, contraception and infertility that some health plan sponsors and health care institutions and providers might object to on religious or moral grounds. These protections are particularly important for people of color and other groups in the United States who have often faced coercive and discriminatory treatment and heightened barriers to coverage and care.

**Applying inappropriate exemptions**

In addition to eliminating important definitions from the 2016 final rule, the proposed rule would also improperly incorporate a pair of exemptions from Title IX: its religious exemption to protections against sex discrimination, and its exemption carving out abortion coverage and care from protections against sex discrimination.

As HHS acknowledged when finalizing the Section 1557 rules in 2016, both of these exemptions were written in the context of the U.S. education system and they are inappropriate for the U.S. health system. For example, students and parents typically have a choice about whether to select a religiously affiliated educational institution; yet, in the health care context, people’s choice of institutions and providers is often limited by geography (e.g., in rural areas) or situation (e.g., emergencies). Congress did not include these exemptions in Section 1557 of the ACA, and adding them in via the proposed rule would be a clear and improper violation of congressional intent.

The proposed rule also exempts entities from compliance if enforcing compliance would violate the Religious Freedom Restoration Act (RFRA), a list of existing federal refusal of care laws, or any similar future federal laws or regulations. This blanket statement of exemption is a departure from the 2016 final rule, which emphasized that laws like RFRA must be applied via case-by-case examination of the facts and circumstances. This marks one more example of the Trump administration’s harmful expansion of refusal of care rights, at the expense of and without any attempt to balance the rights, health or dignity of enrollees and patients. The Guttmacher Institute strongly objected to the Trump administration’s refusal of care rule, which was finalized over such objections in May 2019.

**Amending unrelated regulations**

The proposed rule would go well beyond the 2016 final rule on Section 1557 by eliminating nondiscrimination protections related to gender identity and sexual orientation in 10 other current HHS rules. Despite HHS’s characterization of these changes as “limited conforming amendments,” they encompass a wide array of HHS-related entities and programs, including state Medicaid programs, Medicaid managed care plans, and many private insurance plans.

Combined with the other proposed changes in this rule, the end result could be a return to the pre-ACA situation where discrimination against LGBTQ people was left unchecked. For example, states agencies, marketplaces,
health plans, and insurance agents and brokers could discriminate against LGBTQ people, such as in making eligibility determinations, setting premiums, or offering resources and assistance.

**Weakening Language Access Protections**

The 2016 final rule recognized that language access protections for people with limited English proficiency (LEP) are vital to preventing discrimination based on national origin. By contrast, the proposed rule would roll back several of these protections. Specifically, the proposed rule would eliminate notice requirements about the availability of language assistance services; currently, these notices must be provided via taglines in the top 15 languages spoken by LEP individuals in the state. The proposed rule would also eliminate standards for remote video interpreting standards, instead including standards only for remote audio interpreting services. And the proposed rule would eliminate the recommendation that covered entities develop a “language access plan” to evaluate how best to serve LEP enrollees and patients; under the 2016 final rule, HHS takes into account whether an entity has a language access plan in evaluating whether it is complying with Section 1557.

Language access protections help ensure that enrollees and patients are able to access the coverage and care they need in a timely manner. Without services like translation and interpretation, LEP individuals face heightened barriers to enrolling and making use of a health plan. Similarly, these services improve communication between LEP individuals and their health care providers, including around diagnosis of problems, counseling and decision-making about care options, and instructions about medication and care. All of this is necessary to protect the health of LEP individuals and to address persistent inequities and disparities.

**Narrowing the Rule’s Scope and Eliminating Insurance Protections**

Section 1557 of the ACA applies specifically to “any health program or activity, any part of which is receiving Federal financial assistance, including credits, subsidies, or contracts of insurance, or under any program or activity that is administered by an Executive Agency or any entity established under this title (or amendments).” Congress was clear in its intent to broadly address discrimination in the U.S. health system, including at the insurance level and the provider level. That approach matches that of the ACA writ large, which was an attempt to overhaul numerous aspects of the U.S. health system, and especially health coverage, in order to address persistent and discriminatory barriers that prevented many people from obtaining affordable, comprehensive coverage for all the care they needed.

In delineating the scope of HHS’s enforcement of Section 1557, the 2016 final rule followed the letter and the spirit of the statute. Notably, it makes it clear that a health program or activity receiving federal financial assistance includes entities providing or administering either health-related services or health-related insurance coverage.

**Narrowing the scope**

The proposed rule attempts to reverse that decision and greatly reduce the number of health insurance plans that must abide by Section 1557. HHS essentially is asserting that health coverage does not count as a “health program or activity.” Further, for instances where health insurers are still subject to Section 1557, it would only cover the specific programs and activities that receive federal funding. The end result of these changes would be to drastically narrow Section 1557’s authority over health insurers. For example, currently, a health insurer that participates in the ACA’s marketplaces must abide by Section 1557 for all of its health plans, on or off of the marketplaces; under the proposed rule, plans offered outside of the marketplaces would be exempt. Similarly, HHS makes it clear that the proposed rule would not generally apply to short-term limited duration insurance—plans that in fact deserve heightened scrutiny around discrimination, because of their long history of discriminatory premiums and benefit design.
In addition, under the proposed rule, HHS would only apply the regulations to health programs and activities administered under Title I of the ACA, rather than all HHS-administered program and activities. That would exclude most programs administered by the Centers for Medicare and Medicaid Services, the Centers for Disease Control and Prevention, the Indian Health Service, and many other HHS agencies. This change would be in direct contradiction to the plain language of the ACA.

Eliminating insurance-specific protections

The second major way that the proposed rule backs away from health insurance is by eliminating a series of insurance-specific protections from the 2016 final rule. The 2016 rule lays out a series of insurance industry practices that are prohibited, if applied on the basis of any of the classes protected under Section 1557. That list of practices includes actions like denying or limiting a health insurance policy or coverage of a specific claim; imposing additional cost sharing or other coverage limitations; or using discriminatory marketing practices or insurance benefit designs.

The proposed rule would eliminate these insurance-specific protections, as well as the insurance-related protections specific to gender identity mentioned above. Without these protections and without robust HHS enforcement of Section 1557 in the insurance context, health plans may return to many of their pre-ACA tricks designed to discourage high-cost patients from enrolling in their plan or to restrict how much those patients are able to make use of their coverage. For example, in the absence of government oversight, health plans have discouraged HIV-positive people from enrolling by placing all or most HIV treatment drugs at the highest tier of the plan’s drug formulary.

Weakening Notice and Enforcement Mechanisms

Under the 2016 final rule, covered entities with at least 15 employees must set up a grievance procedure, designate an employee to coordinate the entity’s responsibilities under Section 1557, and provide notice of the entity’s nondiscrimination policies via its employee handbook, website and other locations. The proposed rule would eliminate these notice and grievance procedure requirements, explicitly as a way to reduce costs to health care institutions and despite HHS’s acknowledgment that without these requirements, some individuals will not be able to learn about and exercise their rights under the ACA.

The proposed rule would also roll back the enforcement mechanisms available under the 2016 final rule. In the proposed rule, HHS argues that rather than applying a consistent and robust set of enforcement mechanisms to all of Section 1557, it must instead apply different mechanisms for each protected class (race, color, national origin, age, disability or sex), setting up a confusing set of rules for individuals to navigate and limiting claims of intersectional discrimination. In addition, HHS proposes to reverse its 2016 position and no longer recognize the right of individuals under Section 1557 to file lawsuits in federal court or to receive compensation for monetary damages. The courts themselves have and will likely continue to recognize these rights, but HHS’s proposed rule will, again, hamper individuals’ ability to learn about and exercise their rights.

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In summary, the proposed changes in this rule would violate the letter and the spirit of Section 1557 of the ACA and undermine the right of all enrollees and patients to navigate the U.S. health system free from discrimination. The proposed rule would undermine the rights of LGBTQ individuals, people who need reproductive health care, people of color, people living with disabilities or chronic conditions, and people whose primary language is not English, among many others. For the all of the reasons detailed above, HHS and CMS should not finalize the proposed rule.
We hope you find these comments useful as you consider whether and how to finalize this rule. If you need additional information about the issues raised in this letter, please contact Adam Sonfield in the Institute’s Washington office. He may be reached by phone at 202-296-4012, or by email at asonfield@guttmacher.org.

Thank you for your consideration.

Sincerely,

Rachel Benson Gold
Vice President for Public Policy