



## A BOLD AND INDEPENDENT VOICE FOR THE RIGHTS OF WOMEN AND GIRLS

August 12, 2019

### VIA ELECTRONIC SUBMISSION

Secretary Alex Azar  
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**

Dear Secretary Azar:

The International Women's Health Coalition submits these comments in response to the Department of Health and Human Services' ("HHS", "Department") and the Center for Medicare and Medicaid Services ("CMS") Notice of Proposed Rulemaking ("proposed rule," "NPRM") to express our concerns with the proposed rule entitled "Nondiscrimination in Health and Health Education Programs or Activities," published in the Federal Register on July 14, 2019.

The International Women's Health Coalition (IWHC) has, for 35 years, worked to promote human rights, health, and equality around the world. IWHC's direct experience of partnering with leaders and organizations working on sexual and reproductive health and rights issues in their communities and countries has emphasized the critical importance of removing barriers to health care access, including the need to work to ensure that no individual faces discrimination.

Health care is a human right and a health care provider's personal beliefs should never determine the care that a patient receives. That is why IWHC strongly opposes the proposed elimination or rollback of critical protections guaranteed by Section 1557 of the Affordable Care Act ("ACA") and the 2016 Nondiscrimination in Health Programs or Activities final rule ("2016 final rule"). We demand that this NPRM be rescinded in its entirety. If enacted, this rule will roll back critical protections against discrimination in all aspects of health care.

Critically, IWHC's experience and research on related issues has indicates that rules like this – that prioritize the beliefs of providers over their ethical obligations to provide the best possible care to their patients – exacerbate existing gaps in access to health care. IWHC's global work has shown that refusals of care have the gravest consequences for people who already face multiple forms of discrimination – such as women, LGBTQ individuals, people living in rural areas, and young people – as they seek to overcome barriers that make access to health care a serious challenge.

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In 2017, IWHC hosted a global convening in Montevideo, Uruguay, where experts from 22 countries agreed that the denial of health care services based on personal belief is a violation of human rights. International human rights standards to date do not require states to guarantee a right to “conscientious objection” for health care providers. On the contrary, human rights treaty monitoring bodies have called for limitations on the exercise of conscience claims when states do allow them, in order to ensure that providers do not hinder access to services and thus infringe on the rights of patients. Instead, they direct states to take steps to guarantee patients’ access to services and minimize barriers to care.

A person’s need for evidence-based, medically sound, legal health care services is a provider’s professional and ethical duty, and this should take precedence over their religious or personal beliefs. Particularly in a health care setting, a person’s right to be free of discrimination takes precedence over a provider’s claims of freedom of conscience or religion.

Within the Affordable Care Act, Section 1557 protects individuals from discrimination on the basis of race, color, national origin, sex, (including gender identity, sexual orientation, and sex stereotypes; and pregnancy, childbirth, and related medical conditions), age, and disability in certain health programs or activities. Critically, Section 1557 specifically protects against intersectional discrimination, or discrimination based on multiple protected characteristics, by allowing people to file complaints of such discrimination in one place.

Section 1557’s current rule, the 2016 final rule, explicitly prohibits discrimination on the basis of sex, which includes discrimination on the basis of pregnancy, false pregnancy, termination of pregnancy, or recovery therefrom, childbirth or related medical conditions, sex stereotyping and gender identity. The 2016 final rule also protects individuals with Limited English Proficiency (“LEP”) and individuals with disabilities and/or chronic conditions from discrimination.

While Section 1557 is still the law, this proposed rule attempts to change the administrative implementation in a way that is contrary to the plain language of the law. The NPRM’s proposed changes pose significant risks to those the law is intended to protect, including lesbian, gay, bisexual, transgender, and queer (“LGBTQ”) people, people who need reproductive health care, including abortion, women of color, people living with disabilities and/or chronic conditions, and people whose primary language is not English—all people who already experience significant barriers to accessing health care. The proposed changes could create additional barriers and potentially lead to worse health outcomes, disproportionately impacting those living at the intersections of these identities.

IWHC partners with organizations in the global south that have extensive experience with the ways intersecting identities can compound the forms of discrimination faced by an individual, particularly when seeking health care. A woman might face specific challenges because of her gender; these might be compounded because she identifies as a lesbian, or because she has sought abortion services, or because she comes from an indigenous community. The consequences of these multiple and intersecting forms of discrimination are real, and they compound other challenges she might face in accessing quality health care, including cost and distance to services.

Although Section 1557 is still law, the proposed rule would almost entirely replace the 2016 final rule that made clear what forms of discrimination are prohibited by Section 1557. The proposed rule is not justified and seeks to impermissibly depart from the statutory text of Section 1557 and the 2016 final rule, which was finalized after considerable public

comment, including a request for information and one notice of proposed rulemaking. By replacing most of the 2016 final rule with unclear regulations, the proposed rule, if finalized, would create confusion and could open the door to illegal discrimination.

In direct opposition to the text of Section 1557, the proposed rule improperly seeks to exempt many health insurance plans from the anti-discrimination provisions, as well as any health program or activity run by HHS that was not created by Title I of the ACA. It eliminates regulations pertaining to the fundamental requirement that all beneficiaries, enrollees, applicants, and members of the public receive notice of their rights under Section 1557 and removes important regulations that protect individuals with LEP. It improperly tries to incorporate Title IX's religious exemption, which could permit health care entities controlled by a religious organization to discriminate if the entity claims complying with the sex discrimination protections conflicts with its religious beliefs. The rule attempts to overrule decades of federal court precedent by trying to eliminate protections against discrimination on the basis of gender identity, and completely disregards Supreme Court precedent on discrimination based on sex stereotyping. Although the preamble to the proposed rule acknowledges that Section 1557 prohibits discrimination based on pregnancy, including termination of pregnancy, the Department refuses to state whether it would enforce those protections. Additionally, contrary to the plain language of the law, the proposed rule improperly seeks to incorporate an abortion carveout from Title IX to narrow the protection under Section 1557. This is an attack on all of our civil rights and will harm the very communities and people Section 1557 was intended to protect.

In order to reflect the ACA's clear intent and its overriding purpose of eliminating discrimination in health care, the proposed rule should not be finalized.

## **I. The Proposed Rule Impermissibly Attempts to Dramatically Narrow the Scope of Section 1557**

The 2016 final rule made clear that Section 1557 applies to all health programs and activities that receive federal financial assistance from the Department, all health programs and activities administered by the Department, and state-based marketplaces. The 2016 final rule defines health programs and activities to include all operations of an entity receiving federal financial assistance that is principally engaged in the provision or administration of health-related services or health-related insurance coverage.

The proposed rule attempts to reduce the number of health insurance plans that are covered by claiming that if the issuer of a health plan is "not principally engaged in the business of providing health care (as opposed to health insurance), only its Marketplace plans would be covered and any plans it offers outside the marketplace would not be subject to Section 1557."<sup>1</sup> Additionally, the proposed rule improperly attempts to narrow that application of Section 1557's protections to only the portion of a health care program or activity that received federal financial assistance. These changes unlawfully narrow the scope of Section 1557's application. Rather, the statute is clear that the law's provisions apply broadly 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)." 42 U.S.C. § 18116(a).

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<sup>1</sup> MaryBeth Musumeci et al., *HHS's Proposed Changes to Non-discrimination Regulations under ACA Section 1557*, Kaiser Family Foundation (Jul. 1, 2019), <https://www.kff.org/disparities-policy/issue-brief/hhss-proposed-changes-to-non-discrimination-regulations-under-aca-section-1557/>.

This change is illegal. If it were nevertheless implemented, it would have significant consequences, particularly for consumers who purchase short-term limited duration insurance (“STDLI”). If implemented, the proposed rule would generally not apply to STDLI plans because insurers are no longer considered health care entities, and these specific plans do not receive federal financial assistance.

Short-term plans are notorious for discriminating against consumers based on gender, age, and disability. If implemented, this proposed rule would be harmful to women, especially women of color, for example. The proposed rule would embolden short-term plans to discriminate against women by refusing to cover reproductive health services, such as maternity, contraceptive care or fertility care and coverage, or deny coverage altogether for other conditions unique to women like breast or cervical cancer. A 2018 study for example, found that not a single short-term plan covered maternity care.<sup>2</sup> Short-term plans also discriminate based on gender identity by excluding coverage for transition-related services, such as surgery. Additionally, short-term health plans could charge women higher premiums than men. For example, according to data submitted to Wisconsin insurance regulators, a National Health Insurance Company short-term plan with a \$5,000 deductible would cost \$109 per month for a 40-year-old woman, compared to \$90 per month for a man of the same age.<sup>3</sup>

Women have long been the subject of discrimination in health care.<sup>4</sup> Despite the historic achievements of the ACA, women are still more likely to forego care because of cost,<sup>5</sup> and women – particularly Black women – are far more likely to be harassed by a provider.<sup>6</sup> These barriers mean women are more likely not to receive routine and preventive care than men. Moreover, when women are able to see a provider, women’s pain is routinely undertreated and often dismissed.<sup>7</sup> And due to gender biases and disparities in research, doctors offer women less aggressive treatment, or even no treatment, for conditions such as heart disease.<sup>8</sup>

## **II. The Proposed Rule Impermissibly Attempts to Narrow the Definition of Sex Discrimination**

Sex discrimination in health care has a disproportionate impact on women of color, LGBTQ people, and individuals living at the intersections of multiple identities—resulting in them

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<sup>2</sup> Karen Pollitz et al., *Understanding Short-Term Limited Duration Health Insurance*, Kaiser Family Foundation (Apr. 23, 2018), <https://www.kff.org/health-reform/issue-brief/understanding-short-term-limited-duration-health-insurance/>.

<sup>3</sup> Sarah Lueck, *Key Flaws of Short-Term Health Plans Pose Risks to Consumers*, Ctr. on Budget & Pol’y Priorities (Sept. 20, 2018), <https://www.cbpp.org/research/health/key-flaws-of-short-term-health-plans-pose-risks-to-consumers>.

<sup>4</sup> Prior to the ACA, women were charged more for health care on the basis of sex and were continually denied health insurance coverage for services that only ciswomen, transgender, and gender non-conforming patients need. See *Turning to Fairness*, Nat’l Women’s L. Ctr. 1, 3-4 (2012), [https://nwlc.org/wp-content/uploads/2015/08/nwlc\\_2012\\_turningtofairness\\_report.pdf](https://nwlc.org/wp-content/uploads/2015/08/nwlc_2012_turningtofairness_report.pdf) (noting that while the ACA changed the health care landscape for women in significant ways, women still face additional hurdles).

<sup>5</sup> See Shartzer, et al., *Health Reform Monitoring Survey*, Urban Inst. Health Policy Ctr. (Jan. 2015), <http://hrms.urban.org/briefs/Health-Care-Costs-Are-a-Barrier-to-Care-for-Many-Women.html>.

<sup>6</sup> See *Discrimination in America: Experiences and Views of American Women*, NPR & Harvard T.H. Chan Sch. of Pub. Health (Dec. 2017), <https://cdn1.sph.harvard.edu/wp-content/uploads/sites/21/2017/12/NPR-RWJF-HSPH-Discrimination-Women-Final-Report.pdf>.

<sup>7</sup> See, e.g., Diane E. Hoffmann & Anita J. Tarzian, *The Girl Who Cried Pain: A Bias Against Women in the Treatment of Pain*, 29:1 J. of L., Med. & Ethics 13, 13-27 (2001).

<sup>8</sup> See, e.g., Judith H. Lichtman et al., *Symptom Recognition and Healthcare Experiences of Young Women with Acute Myocardial Infarction*, 10 J. of the Am. Heart Ass’n 1 (2015).

paying more for health care, receiving improper diagnoses at higher rates, being provided less effective treatments, and sometimes being denied care altogether. As the first broad prohibition against sex-based discrimination in health care, Section 1557 is crucial to ending gender-based discrimination in the health care industry. In addition to personal stories, there have been surveys, studies, and reports documenting discrimination in health care against these communities and their families.

#### **a. Sex discrimination based on gender identity**

The 2016 final rule clarified that Section 1557's prohibition on sex discrimination includes a prohibition of discrimination on the basis of gender identity, including transgender and/or nonbinary status. The proposed rule illegally attempts to erase all reference to the ACA's protections against discrimination on the basis of gender identity. It illegally purports to allow a health care provider to refuse to treat someone because of their gender identity. For example, a doctor could refuse to treat a transgender person for a cold or a broken bone, simply because of their gender identity.

In addition, the 2016 final rule clarified that insurance companies cannot categorically exclude or deny coverage for gender-affirming care. The proposed rule illegally attempts to again open the door to insurance companies categorically excluding coverage of gender-affirming care from their plans or denying individuals coverage of procedures used for gender affirmation. Gender-affirming care is medically necessary and often life-saving for transgender, nonbinary, and gender nonconforming people experiencing gender dysphoria.<sup>9</sup>

The 2016 final rule made clear that issuers cannot deny health services or impose additional costs on services that are ordinarily or exclusively available to individuals of one sex or gender based on the fact that the individual's recorded sex in medical or insurance records differs from the one to which such health services are ordinarily or exclusively available. The proposed rule impermissibly tries to permit providers and insurers to refuse to provide and cover certain reproductive health care for transgender, nonbinary, and gender nonconforming people.

Additionally, Section 1557 and the 2016 final rule prohibit covered entities from denying, limiting, or imposing additional cost-sharing for services based on sex or gender. If implemented, the proposed rule would eliminate the regulations that specifically address cost-sharing, adding confusion about whether covered entities may impose additional financial burdens on transgender, nonbinary, and gender nonconforming individuals.

In the United States, transgender, nonbinary, and gender nonconforming people already experience high rates of discrimination and harassment in health care. According to the 2015 U.S. Transgender Survey, 33 percent had at least one negative experience in a health care setting relating to their gender identity in the past year.<sup>10</sup> These experiences might include having a provider deliberately misgender or use the wrong name when referring to them, the use of harsh or abusive language, and unwanted physical contact. All of these experiences may discourage people from seeking medical care, and they have serious and tangible impacts on the quality of care people receive.

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<sup>9</sup> Nat'l Health Law Program, et al., Medicaid as an LGBTQ Reproductive Justice Issue: A Primer, Gender-affirming Care in Medicaid 1 (2019), <https://healthlaw.org/resource/medicaid-as-an-lgbtq-reproductive-justice-issue-a-primer/>.

<sup>10</sup> S.E. James, et al., Nat'l Ctr. for Transgender Equality, Report Of The 2015 U.S. Transgender Survey 96-97 (2016), <https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf>.

Globally, the same is true. Transgender people face extreme discrimination and violence in many places, and their identities are often criminalized. The global community has begun taking small steps toward combatting discrimination and persecution of transgender and gender non-conforming people throughout the world through documents like the Yogyakarta Principles, an agreement by an international gathering of human rights experts and jurist that clearly states that “Human beings of all sexual orientations and gender identities are entitled to the full enjoyment of all human rights,” and “(e)veryone is entitled to enjoy all human rights without discrimination on the basis of sexual orientation or gender identity. Everyone is entitled to equality before the law and the equal protection of the law without any such discrimination whether or not the enjoyment of another human right is also affected. The law shall prohibit any such discrimination and guarantee to all persons equal and effective protection against any such discrimination.”

The Yogyakarta Principles call on states to both “adopt appropriate legislative and other measures to prohibit and eliminate discrimination in the public and private spheres on the basis of sexual orientation and gender identity” and to “take account of the manner in which such discrimination may intersect with other forms of discrimination.” While the 2016 final rule was a step toward bringing the United States into line with this growing global consensus, the proposed rule would be a massive regression.

#### **b. Sex discrimination based on sex stereotyping**

The 2016 final rule reiterated that sex stereotyping is a prohibited form of discrimination under the 1989 Supreme Court decision, *Price Waterhouse v. Hopkins*<sup>11</sup>. The proposed rule attempts to erase established Supreme Court precedent recognizing that discrimination on the basis of sex includes discrimination on the basis of sex stereotypes. This could result in health providers thinking they could turn a patient away because the patient does not conform with traditional stereotypes about their sex. Federal courts have applied the reasoning of *Price Waterhouse* to both LGBTQ and non-LGBTQ people seeking relief for sex discrimination.

#### **c. Sex discrimination based on pregnancy, including termination of pregnancy**

Sex discrimination takes many forms and has the potential to occur at every step in the health care system—from obtaining insurance coverage to receiving proper diagnosis and treatment to harassment by a provider. Such discrimination has serious adverse impacts on the lives of women, causing them to pay more for health care and to risk receiving improper diagnoses and less effective treatments. The effects of sex discrimination for women of color may be compounded by other forms of discrimination they face, including racial discrimination and discrimination based on language proficiency.

The 2016 final rule made clear that sex discrimination under Section 1557 includes discrimination on the basis of pregnancy, false pregnancy, termination of pregnancy, or recovery therefrom, childbirth or related conditions. The proposed rule attempts to roll back these protections. Although HHS acknowledges in the preamble to this proposed rule that the prohibition against sex discrimination includes termination of pregnancy, it refuses to state whether the Department would enforce those protections and proposes to delete the 2016 final rule's clarification that the ban on sex discrimination includes all pregnancy related care. In doing so, the Department illegally attempts to eliminate the express protections that apply to someone who has had an abortion or has experienced a

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<sup>11</sup> 490 U.S. 228 (1989).

miscarriage or ectopic pregnancy and needs care for those conditions. While the scope of protection under Section 1557 is clear, without unambiguous implementing regulations and enforcement, illegal discrimination is likely to flourish.

The proposed rule also seeks to unlawfully incorporate Title IX's "Danforth Amendment", which carves out abortion care and coverage from the ban on discrimination of sex in the education context. Congress did not include the Title IX exceptions, including the Danforth Amendment, either explicitly or by reference, in Section 1557. The proposed rule's unlawful incorporation of the Danforth Amendment is yet another Trump-Pence administration attack on abortion care. These attacks could embolden illegal discrimination that will fall heaviest on those least able to seek health care elsewhere, including women living in rural areas and women of color, who already face harassment and discrimination by providers during pregnancy, contributing to Black and Native American women's unacceptably high rates of health related pregnancy complications and death.

The discrimination allowed under this proposed rule will serve to amplify existing so-called "conscience protections," massively expanded under the Trump administration, which allow medical providers to refuse provision of abortion and other sexual and reproductive health care and to create a system where people who are pregnant may not be able to access the care they need. Additional denial of care relating to abortion services is wholly unnecessary and would further erode access to abortion services.

While health care professionals are entitled to their religious beliefs, prioritizing providers' individual concerns over their duty to provide services threatens the health care profession's integrity and objectives. The 2016 rule is consistent with this prioritization of a patient's right to health care. It recognizes that individuals who object to certain services are free to enter the health care profession and specialize in fields in which their abilities to provide comprehensive services is not undermined by their personal beliefs. Conversely, there are countless scenarios and reasons – including cost, distance, and insurance coverage – why patients might not be able to simply choose another provider.

This proposed rule violates the ethical principle of "do no harm" and will have grave consequences for women, especially those who are already more vulnerable and marginalized. A woman denied an abortion might have no choice but to continue an unintended pregnancy. She may resort to a clandestine, unsafe abortion, with severe consequences for her health or risk of death. She might be forced to seek out another provider, which can be costly in time and expense. All of these scenarios can lead to health problems, mental anguish, and economic hardship.

#### **d. Religious Exemption**

The 2016 final rule intentionally did not include any religious exemption. The inclusion of a religious exemption, either explicitly or by reference, is contrary to the statutory language in Section 1557, which does not include any exceptions.

The proposed rule attempts to impermissibly apply Title IX's religious exemption to Section 1557's prohibition on sex discrimination. The Department's attempt to incorporate a religious exemption violates the plain language of the statute and is contrary to the express purpose of Section 1557. If implemented, this could allow for religiously-affiliated hospitals and other health care entities to discriminate against patients based on sex, disproportionately harming LGBTQ people, people seeking reproductive health services, including abortion care, and those living at the intersection of these identities.

Allowing a religious exemption to Section 1557's protection against sex discrimination could have far reaching consequences. Incorporating Title IX's religious exemption could create new instances in which health care providers, including insurance companies, hospital, doctor, or nurses, can allow their beliefs to determine patient care, opening the door to illegal discrimination. This could impact a broad range of health care services, including birth control, sterilization, certain fertility treatments, abortion, gender-affirming care, and end of life care. Moreover, there is already a proliferation in the types of entities that are now emboldened to use religious beliefs to discriminate against patients and the number of religiously-affiliated entities that provide health care and related services and refuse to provide care based on religious beliefs.<sup>12</sup> The proposed rule could encourage these entities to engage in illegal discrimination.

Freedom of conscience is enshrined internationally in instruments such as the Universal Declaration of Human Rights and the International Covenant on Civil and Political Rights (ICCPR). However, no international human rights standard recognizes a right to "conscientious objection" in the context of health care. Religious anti-choice groups have appropriated the term and extended it to the realm of health care. In doing so, they distort the historical use of the term and contribute to obstructing access to sexual and reproductive health care. Particularly in the case of abortion, they demonize a routine health procedure and those who provide or seek it. Claims of "conscientious objection" to abortion place the preferences of providers ahead of the rights of patients.

Providers and institutions claiming personal or religious beliefs to justify the refusal to provide services undermine the objectives of their profession, which is to provide health care to those who need it. Medical ethics guidelines require providers to prioritize patient care over conscience claims. Current guidelines by the International Federation of Gynecology and Obstetrics (FIGO) state that a doctor objecting to abortion based on conscience "has an obligation to refer the woman to a colleague who is not in principle opposed to termination." The current World Health Organization (WHO) safe abortion guidance further stipulates that the referral must be to someone in the same or another easily accessible health care facility. If a referral is not possible, the objecting provider is obligated to provide a safe abortion to preserve the woman's life and to prevent risks to her health. Any woman who presents with complications due to abortion must receive professional care with urgency and respect, as with any other emergency case.

Religious exemptions disproportionately harm LGBTQ people, especially those who are transgender, nonbinary, gender nonconforming. LGBTQ people are often refused health care services because of their sexual orientation and/or gender identity. For example, 8 percent of LGBTQ people were refused health care because of their sexual orientation, and 6 percent were refused care related to their sexual orientation. Similarly, 29 percent of transgender people were refused health care because of their gender identity and 12 percent were refused gender-affirming health care. When LGBTQ people are refused treatment, it becomes difficult or impossible to find another provider, especially for those living in rural areas and for transgender people.

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<sup>12</sup> See, e.g., Lois Uttley, et al., *Miscarriage of Medicine: the Growth of Catholic Hospitals and the Threat to Reproductive Health Care*, Am. Civil Liberties Union & Merger Watch (2013), <https://www.aclu.org/files/assets/growth-of-catholic-hospitals-2013.pdf>.

### **III. The Proposed Rule Could Embolden Providers to Discriminate Against Individuals in Title X-funded Health Centers**

This proposed rule attempts to sow confusion about the critical protections against discrimination to which Title X-funded providers and others must adhere to. Although Section 1557 is still the law of the land, if implemented, the proposed rule could embolden providers to participate in the Title X program and other similar programs even though they intend to allow their personal beliefs to dictate patient care. We believe that providers currently enrolled in the program would continue to act in good faith and would not discriminate against those obtaining health care. However, the Trump-Pence administration has clearly demonstrated its preference for providers who would use their religious or moral beliefs as a license to discriminate over the needs of patients and this proposed rule would further that goal.

In many states, a Title X-funded provider is one of the few places women of color can access reproductive health care and preventive health care services and it is critical that those providers are not discriminating against the individuals that are able to make it through their doors. Title X-funded health centers are a lifeline for quality health care for underserved communities. Providers administer gynecological exams, contraception, counseling, pap tests, breast exams and screenings for HIV, AIDS and other STIs, and all services are provided confidentially. Their adherence to the protections Section 1557 is critical given their role in these underserved communities. Additionally, Title X health care providers also offer services for foreign-born individuals who are less likely to have coverage (46 percent) than U.S.-born people (75 percent). For those who have limited options for care, these services, which are available at an affordable price at Title X-funded health centers, can mean the difference of a person receiving care or going without care. Given that many individuals who seek care at a Title X clinic live at the intersection of identities protected by Section 1557, the fact that the proposed rule seeks to roll back the protections for those individuals is both contrary to the plain language and spirit of the law.

### **IV. The Proposed Rule Impermissibly Attempts to Amend Unrelated Regulations to Exclude Sexual Orientation and Gender Identity Protections**

The 2016 final rule did not touch other HHS health care regulations. The proposed rule attempts to erase all references to gender identity and sexual orientation in all HHS health care regulations. If implemented, this rule would eliminate express prohibitions on discrimination based on gender identity and sexual orientation from regulations that govern a range of health care programs, including private insurance and education programs. This could result in less health care and poorer health outcomes for communities across the country.

### **V. The Proposed Rule Impermissibly Attempts to Eliminate Language Access Protections**

Over 21 percent of the U.S. population, or 66 million people, speak a language other than English at home, with 25 million of them speaking English less than “very well” and thus considered LEP.<sup>13</sup>

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<sup>13</sup> U.S. Census Bureau, *2017 American Community Survey 1-Year Estimates: Table S1603 Characteristics of People by Language Spoken at Home*, [https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS\\_17\\_1YR\\_S1603&prodType=table](https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_17_1YR_S1603&prodType=table) (last visited Jul. 17, 2019); U.S. Census Bureau, *2017 American Community Survey 1-Year Estimates: Table S1601 Language Spoken at Home*

For LEP individuals, language differences often compound existing barriers to access and receiving appropriate care. LEP often makes it difficult for many to navigate an already complicated health care system, especially when it comes to medical or insurance terminology. Moreover, these barriers are often compounded by discrimination based on national origin, immigration status, race, ethnicity, sexual orientation, and gender/gender identity.

Without the regulatory requirements outlined in the current regulations, people with LEP could face additional challenges in access to culturally and linguistically appropriate care, including information about accessing services and health insurance. In particular, discussions about sexual and reproductive care can be sensitive and raise issues of privacy and confidentiality. It is critical that individuals have access to adequate language services, in a private and confidential setting, allowing for information about and access to sexual and reproductive health care to be available in a culturally and linguistically competent manner. Section 1557 provides these protections. The proposed regulations would make their scope less clear, causing confusion and opening the door to illegal discrimination.

#### **a. Remote interpreting services**

The 2016 final rule includes standards for video remote interpreting services. The proposed rule attempts to remove video remote interpreting standards and require only audio remote interpreting for spoken language interpretation. The type of interpreting during a medical visit should depend on the type of encounter. Keeping the current standard allows providers to determine which technology is appropriate and that when an entity uses video, it is high quality and without lagging.

#### **b. Taglines**

The 2016 final rule requires covered entities to include taglines in the top fifteen languages spoken by individuals with LEP in the state on all significant documents. Taglines, or short statements in various languages informing individuals of their right to language assistance and how to seek such assistance, must be included in significant publications, including notices of nondiscrimination. The proposed rule illegally seeks to eliminate the requirement that entities use in-language taglines. This proposal will cause harm and should not be finalized.

#### **c. Language access plans**

Protections around language access have long included recommendations around development of language access plans to help covered entities better meet the needs of people with LEP. The 2016 final rule did not require covered entities to develop language access plans but said if an entity has a language access plan, the Office of Civil Rights (“OCR”) must consider it when evaluating compliance. The proposed rule attempts to eliminate recommendations that entities develop language access plans and remove the consideration requirement. The development of language access plans should remain an item that supports an entity’s compliance with the law.

By eliminating critical protections for LEP individuals seeking care, the administration is discouraging entities from meeting individuals where they are, making health care access inaccessible and often convoluted for marginalized or linguistically isolated communities. Language proficiency should not determine whether or not people have access to care or the quality of a person's care.

## **VI. The Proposed Rule Impermissibly Attempts to Eliminate Prohibitions on Discrimination in Insurance Plan Benefit Design and Marketing**

Over 133 million people in the U.S. live with at least one chronic condition.<sup>14</sup> Over 61 million people in the U.S. live with a disability.<sup>15</sup>

Before the ACA, people with serious and/or chronic health conditions were often [denied health insurance coverage](#) or paid high prices for substandard plans with [coverage exclusions](#), leaving many people unable to afford the health care they needed. Under the ACA, insurers can no longer charge higher premiums or deny coverage for people with pre-existing conditions. These protections have been lifesaving for many people.

Under the 2016 final rule, covered entities are prohibited from designing benefits that discourage enrollment by persons with significant health needs. For example, insurers are prohibited from placing all or most prescription drugs used to treat a specific condition, such as HIV prescriptions, on a plan's most expensive tier.<sup>16</sup> Additionally, covered entities are prohibited from using discriminatory marketing practices, such as those “designed to encourage or discourage particular individuals from enrolling in certain health plans.”<sup>17</sup> The proposed rule improperly attempts to eliminate these prohibitions.

The proposed rule would make it harder for LGBTQ people to afford coverage and care. The final rule's prohibition on discriminatory plan benefit designs helped LGBTQ people living with HIV get the medications they need. Due to systemic barriers to health care, LGBTQ have a “higher prevalence and earlier onset of disabilities” and disproportionately experience chronic conditions,<sup>18</sup> including HIV.<sup>19</sup> HIV disproportionately affects gay, bisexual, and queer men of color and transgender women of color.<sup>20</sup> For example, more than 25 percent of Black and Brown transgender women are living with HIV,<sup>21</sup> and 60 percent (10,070) of Black or African American individuals who received an HIV diagnosis in

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<sup>14</sup> *The Growing Crisis of Chronic Disease in the United States*, P'ship to Fight Chronic Disease, [https://www.fightchronicdisease.org/sites/default/files/docs/GrowingCrisisofChronicDiseaseintheUSfactsheet\\_81009.pdf](https://www.fightchronicdisease.org/sites/default/files/docs/GrowingCrisisofChronicDiseaseintheUSfactsheet_81009.pdf) (last visited Jul. 17, 2019).

<sup>15</sup> Press Release, Ctrs. for Disease Control & Prevention, *CDC: 1 in 4 US Adults Live with a Disability* (Aug. 16, 2018, 1:00 PM), <https://www.cdc.gov/media/releases/2018/p0816-disability.html>.

<sup>16</sup> MaryBeth Musumeci et al., *HHS's Proposed Changes to Non-discrimination Regulations under ACA Section 1557*, Kaiser Family Foundation (Jul. 1, 2019), <https://www.kff.org/disparities-policy/issue-brief/hhss-proposed-changes-to-non-discrimination-regulations-under-aca-section-1557/>.

<sup>17</sup> MaryBeth Musumeci et al., *HHS's Proposed Changes to Non-discrimination Regulations under ACA Section 1557*, Kaiser Family Foundation (Jul. 1, 2019), <https://www.kff.org/disparities-policy/issue-brief/hhss-proposed-changes-to-non-discrimination-regulations-under-aca-section-1557/>.

<sup>18</sup> *Intersecting Injustice: A National Call to Action* 63 (Lourdes Ashely Hunter, Ashe McGovern & Carla Sutherland eds., 2018), [http://socialjusticesexuality.com/intersecting\\_injustice/](http://socialjusticesexuality.com/intersecting_injustice/).

<sup>19</sup> *Intersecting Injustice: A National Call to Action* 48, 63 (Lourdes Ashely Hunter, Ashe McGovern & Carla Sutherland eds., 2018), [http://socialjusticesexuality.com/intersecting\\_injustice/](http://socialjusticesexuality.com/intersecting_injustice/).

<sup>20</sup> *Intersecting Injustice: A National Call to Action* 63-64 (Lourdes Ashely Hunter, Ashe McGovern & Carla Sutherland eds., 2018), [http://socialjusticesexuality.com/intersecting\\_injustice/](http://socialjusticesexuality.com/intersecting_injustice/).

<sup>21</sup> *Intersecting Injustice: A National Call to Action* 64 (Lourdes Ashely Hunter, Ashe McGovern & Carla Sutherland eds., 2018), [http://socialjusticesexuality.com/intersecting\\_injustice/](http://socialjusticesexuality.com/intersecting_injustice/).

2017 were gay or bisexual men.<sup>22</sup> Further, 26 percent of gay men, 36 percent of bisexual women, 36 percent of lesbian women, 40 percent of bisexual men experience a form of disability.<sup>23</sup> Additionally, 28 percent of transgender, nonbinary, and gender nonconforming people experience a form of disability.<sup>24</sup> The proposed rule would disproportionately impact LGBTQ people of color living with disabilities and chronic conditions.

## **VII. The Proposed Rule Impermissibly Attempts to Undermine Notice and Enforcement Requirements and Remedies**

### **a. Nondiscrimination notice and grievance procedure requirements**

The 2016 final rule requires covered entities with at least 15 employees to adopt a grievance procedure and designate at least one employee to coordinate its Section 1557 responsibilities.<sup>25</sup> The 2016 final rule also requires covered entities to provide notice of nondiscrimination policies in significant communications, in physical locations where the entity interacts with the public, and on the home page of their website. The notice of nondiscrimination must include information about the characteristics protected from discrimination under Section 1557, the availability of and how to access auxiliary aids and services, the availability of and how to access language assistance services, contact information for the designated employee coordinating the entity's Section 1557 responsibilities, the entity's grievance procedures, and complaint procedures for OCR. The proposed rule improperly attempts to eliminate these provisions entirely.

Notices of nondiscrimination are critical for women and LGBTQ people. Notices tell individuals that an entity cannot discriminate and what to do if they face discrimination, including how to file a complaint with OCR.

### **b. Private right of action and compensatory damages**

The 2016 final rule, like the statute itself, allows for a private right of action in federal court. The proposed rule attempts to eliminate the regulatory provisions recognizing private right of action in federal court. Additionally, the 2016 final rule allows for money damages for violations of Section 1557 in both administrative and judicial actions brought under the regulation. The proposed rule attempts to eliminate the regulatory provision providing that money damages are available to those who are injured by violations of the statute.

### **c. Enforcement Mechanisms**

Section 1557 made it so individuals seeking to enforce their rights would not be limited to only the remedies provided to a particular protected group. Under the plain language of Section 1557, individuals have access to any and all of the remedies under any of the cited statutes, including Title VI, Title IX, Section 504 of the Rehabilitation Act, and the Age Discrimination Act, regardless of the type of discrimination an individual faced. The

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<sup>22</sup> *HIV and African Americans*, Ctrs. for Disease Control & Prevention, <https://www.cdc.gov/hiv/group/raciaethnic/africanamericans/index.html> (last updated March 19, 2019).

<sup>23</sup> Disabled World, *LGBT and Disability: Information, News and Fact Sheets*, <https://www.disabled-world.com/disability/sexuality/lgbt/> (last updated Feb. 7, 2019).

<sup>24</sup> S.E. James, et al., Nat'l Ctr. for Transgender Equality, Report Of The 2015 U.S. Transgender Survey 247 (2016), <https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf>.

<sup>25</sup> MaryBeth Musumeci et al., *HHS's Proposed Changes to Non-discrimination Regulations under ACA Section 1557*, Kaiser Family Foundation (Jul. 1, 2019), <https://www.kff.org/disparities-policy/issue-brief/hhss-proposed-changes-to-non-discrimination-regulations-under-aca-section-1557/>.

proposed rule attempts to limit remedies and enforcement mechanisms that are available to those who are discriminated against by claiming that the remedies and enforcement mechanisms for each protected characteristic (race, color, national origin, age, disability or sex) are different and limited to those available under their referenced statute. As a result, the proposed rule would create a confusing mix of legal standards and available remedies under a single law, and could limit claims of intersectional discrimination, going against the text and intent of Section 1557.

Furthermore, the proposed rule would exacerbate negative consequences resulting from conscience-based refusals of care. In contexts where laws and policies permit conscience-based refusals of care, there are stipulations that require health care providers who refuse to provide care to refer their patient to a willing provider, or to carry out those critical services such as abortion in case of an emergency or if no one else is available. Evidence shows, however, that even where regulations are clearly enumerated to limit the exercise of conscience-based refusals, they are nearly ineffective and costly to enforce, resulting in harmful consequences to patients' health and well-being.<sup>26</sup> Thus, IWHC strongly urges that this proposed rule be halted in order to avoid perpetuating discrimination in health care.

### **VIII. Conclusion**

This proposed rule could impose wide ranging harm, particularly falling hardest upon our most underserved populations who already struggle to access health care. The proposed rule is just the latest attack from the Trump-Pence administration on people seeking reproductive health care, including abortion, LGBTQ individuals, individuals with LEP, including immigrants, those living with disabilities, and people of color. Moreover, this rule would embolden compounding levels of discrimination against those who live at the intersection of these identities. The proposed rule is dangerous and contravenes the plain language of Section 1557, specifically, and the ACA broadly.

For the reasons detailed above, HHS and CMS should not finalize the proposed rule and redirect their efforts to advancing health care access and equity for all.

Thank you for the opportunity to submit comments on the proposed rule.

Sincerely,

Nina Besser Doorley  
Senior Program Officer  
International Women's Health Coalition

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<sup>26</sup> Louise Anne Keogh et al., Conscientious objection to abortion, the law and its implementation in Victoria, Australia: perspectives of abortion service providers, BMC Medical Ethics (2019). <https://doi.org/10.1186/s12910-019-0346-1>