

August 12, 2019

#### VIA ELECTRONIC SUBMISSION

The Honorable Alex Azar Secretary 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 American Public Health Association, a diverse community of public health professionals that champions the health of all people and communities, appreciates the opportunity to provide comments on the proposed rule, Nondiscrimination in Health and Health Education Programs or Activities, ("proposed rule"), issued by the Department of Health and Human Services on June 14, 2019. APHA strongly opposes the proposed elimination or rollback of critical protections guaranteed by Section 1557 of the Affordable Care Act and the 2016 Nondiscrimination in Health Programs or Activities final rule ("2016 final rule") and urges that the proposed rule is rescinded in its entirety. The proposed changes pose a significant threat to public health by removing health care discrimination protections for the many marginalized populations, essentially reducing access to health care and perpetuating health inequities.

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.

APHA wholly disagrees with the Department's argument that the proposed rule will ensure "the civil rights of *all* individuals who access or seek to access health programs or activities of covered entities under Section 1557 of the Patient Protection and Affordable Care Act." In fact, by repealing and retracting existing nondiscrimination protections, the department's actions willfully jeopardize the health and well-being of lesbian, gay, bisexual, transgender, queer, nonbinary and gender nonconforming people, people who need reproductive health care, including abortion, women of color, and individuals with disabilities and/or limited English proficiency -- all people who already experience significant barriers to accessing health care and poorer health outcomes. The proposed changes would create additional barriers and potentially lead to worse health outcomes, disproportionately impacting those living at the intersections of these identities.

## The proposed rule would narrow the definition of sex discrimination, effectively condoning and perpetuating health-harming discrimination and stigma and reducing access to health care.

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 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 health care. Among the numerous changes presented in the proposed rule which undermine select populations' meaningful access to care and protection from discrimination, the complete repeal of "§ 92.4 Definitions" is one of the most harmful to public health.

### 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 references to the ACA's protections against discrimination on the basis of gender identity. The proposed rule also 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.

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% had at least one negative experience in a health care setting relating to their gender identity in the past year.<sup>2</sup> Rates were higher for Native respondents (50%), Middle Eastern respondents

<sup>&</sup>lt;sup>1</sup> Nondiscrimination in Health and Health Education Programs or Activities, 84 *Fed. Reg.* 27846-27895, 27846 (proposed on June 14, 2019), <a href="https://www.govinfo.gov/content/pkg/FR-2019-06-14/pdf/2019-11512.pdf">https://www.govinfo.gov/content/pkg/FR-2019-06-14/pdf/2019-11512.pdf</a>.

<sup>&</sup>lt;sup>2</sup> S.E. James, et al., Nat'l Ctr. for Transgender Equality, Report Of The 2015 U.S. Transgender Survey 96-97 (2016), <a href="https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf">https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf</a>.

(40%), multiracial respondents (38%), and respondents with disabilities (42%).<sup>3</sup> According to a 2018 study from the Center for American Progress, 23% had a provider intentionally misgender or use the wrong name for them, 21% had a provider use harsh or abusive language when treating them,<sup>4</sup> and 29% experienced unwanted physical contact, such as fondling, sexual assault, or rape, from a provider.<sup>5</sup> The proposed rule could impermissibly open the door to further discrimination.

#### 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>6</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.

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. 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 miscarriage or ectopic pregnancy and
needs care for those conditions.

#### Religious Exemption

The 2016 final rule intentionally <u>did not</u> 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

<sup>&</sup>lt;sup>3</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.

<sup>&</sup>lt;sup>4</sup> Shabab Ahmed Mirza & Caitlin Rooney, *Discrimination Prevents LGBTQ People from Accessing Health Care*, Ctr. for Am. Progress (Jan. 18, 2018, 9:00 AM), <a href="https://www.americanprogress.org/issues/lgbt/news/2018/01/18/445130/discrimination-prevents-lgbtq-people-accessing-health-care/">https://www.americanprogress.org/issues/lgbt/news/2018/01/18/445130/discrimination-prevents-lgbtq-people-accessing-health-care/</a>.

Shabab Ahmed Mirza & Caitlin Rooney, *Discrimination Prevents LGBTQ People from Accessing Health Care*, Ctr. for Am. Progress (Jan. 18, 2018, 9:00 AM), <a href="https://www.americanprogress.org/issues/lgbt/news/2018/01/18/445130/discrimination-prevents-lgbtq-people-accessing-health-care/">https://www.americanprogress.org/issues/lgbt/news/2018/01/18/445130/discrimination-prevents-lgbtq-people-accessing-health-care/</a>.

<sup>&</sup>lt;sup>6</sup> 490 U.S. 228 (1989).

of these identities. Incorporating Title IX's religious exemption allows for health care providers, including insurance companies, hospitals, doctors, or nurses, to 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, genderaffirming care and end of life care.

The proposed changes ultimately strengthen systemic and institutional forms of discrimination against these vulnerable populations and further contributes to existing disparities, such as increased likelihood of social alienation, homelessness, financial instability, substance use (as a coping mechanism for transphobic discrimination and mistreatment), HIV vulnerability, incarceration, psychological distress, suicidal ideation, suicide attempts, suicide and homicide. 7,8,9,10,11

#### The proposed rule would eliminate language access protections.

Over 21% 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 are considered LEP. 12 For LEP individuals, language differences often compound existing barriers to access and receiving appropriate care.

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 appropriate and 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.

Without adequate language assistance services, LEP individuals face difficulty enrolling in and accessing health programs and activities. Unfamiliarity with the health care system arises from unfamiliarity with its cultural norms, vocabulary, and procedures. Data and stories demonstrate

<sup>8</sup> Transgender Law Center. The state of transgender California: results from the 2008 California Transgender Economic Health Survey. Available at: <a href="http://transgenderlawcenter.org/wp-content/uploads/2012/07/95219573">http://transgenderlawcenter.org/wp-content/uploads/2012/07/95219573</a>-The-State-of-Transgender-California.pdf. Accessed January 24, 2017.

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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,

https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS\_17\_1YR\_S1601&prodType=table (last visited Jul. 17, 2019).

<sup>&</sup>lt;sup>7</sup> Id.

<sup>&</sup>lt;sup>9</sup> Bradford J, Reisner SL, Honnold JA, Xavier J. Experiences of transgender-related discrimination and implications for health: results from the Virginia Transgender Health Initiative Study. Am J Public Health. 2013;103:1820-1829.

<sup>&</sup>lt;sup>10</sup> Center for American Progress. The unfair criminalization of gay and transgender youth: an overview of the experiences of LGBT youth in the juvenile justice system. Available at:

youth/. Accessed January 24, 2017.

II Equity Project. Hidden injustice: lesbian, gay, bisexual, and transgender youth in juvenile courts. Available at: http://www.nclrights.org/wp-content/uploads/2014/06/hidden\_injustice.pdf. Accessed January 24, 2017.

<sup>&</sup>lt;sup>12</sup> U.S. Census Bureau, 2017 American Community Survey 1-Year Estimates: Table S1603 Characteristics of People by Language Spoken at Home,

that individuals with LEP often forgo primary care altogether, as a result of not understanding how to fill out enrollment applications in English or inaccurately translated non-English languages, not understanding the benefits and costs of services in a health plan, or not having the appropriate cultural and language brokers to communicate with English-speaking physicians and pharmacists.

# The proposed rule would redefine 'covered entities', significantly narrowing the scope of Section 1557; a change that would favor insurers and puts the health of vulnerable patient populations at risk.

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." 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 and would severely limit the extent to which the department can ensure the civil rights of individuals seeking to health care in the United States. This deregulation of health insurers puts the health of millions at risk and is likely to result in greater numbers of uninsured Americans, discriminatory out-of-pocket costs, and increased frequency of delayed and/or forgone health care.

## The proposed rule would eliminate prohibition of 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.

<sup>&</sup>lt;sup>13</sup> MaryBeth Musumeci et al., *HHS's Proposed Changes to Non-discrimination Regulations under ACA Section 1557*, Kaiser Family Foundation (Jul. 1, 2019), <a href="https://www.kff.org/disparities-policy/issue-brief/hhss-proposed-changes-to-non-discrimination-regulations-under-aca-section-1557/">https://www.kff.org/disparities-policy/issue-brief/hhss-proposed-changes-to-non-discrimination-regulations-under-aca-section-1557/</a>.

<sup>&</sup>lt;sup>14</sup> The Growing Crisis of Chronic Disease in the United States, P'ship to Fight Chronic Disease, <a href="https://www.fightchronicdisease.org/sites/default/files/docs/GrowingCrisisofChronicDiseaseintheUSfactsheet">https://www.fightchronicdisease.org/sites/default/files/docs/GrowingCrisisofChronicDiseaseintheUSfactsheet</a> 81009.pdf (last visited Jul. 17, 2019).

<sup>&</sup>lt;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), <a href="https://www.cdc.gov/media/releases/2018/p0816-disability.html">https://www.cdc.gov/media/releases/2018/p0816-disability.html</a>.

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. 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." The proposed rule improperly attempts to eliminate these prohibitions.

## The proposed rule would remove sexual orientation and gender identity protections from unrelated regulations affecting other health care programs.

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.

Prior to the passage of the ACA, being transgender was treated as being a pre-existing condition. As a result, transgender people could not get insurance coverage or affordable insurance. Under the proposed rule, states and Marketplaces could discriminate against LGBTQ, nonbinary and gender nonconforming people in eligibility determinations, enrollment periods, and more. Similarly, issuers could inquire about an applicant's sexual orientation or gender identity and use that information for underwriting or determining insurability. As a result, LGBTQ people would face additional barriers to getting the health care they need.

## The Department of Health and Human Services and Centers for Medicare and Medicaid Services should not finalize the proposed rule.

The proposed rule will only increase barriers to care for already marginalized populations, leading to more pronounced health disparities and inequities, ultimately pushing us further away from the Healthy People vision: A society in which all people live long, healthy lives.

Sincerely.

Georges C. Benjamin, MD

**Executive Director** 

<sup>&</sup>lt;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), <a href="https://www.kff.org/disparities-policy/issue-brief/hhss-proposed-changes-to-non-discrimination-regulations-under-aca-section-1557/">https://www.kff.org/disparities-policy/issue-brief/hhss-proposed-changes-to-non-discrimination-regulations-under-aca-section-1557/</a>.

<sup>&</sup>lt;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), <a href="https://www.kff.org/disparities-policy/issue-brief/hhss-proposed-changes-to-non-discrimination-regulations-under-aca-section-1557/">https://www.kff.org/disparities-policy/issue-brief/hhss-proposed-changes-to-non-discrimination-regulations-under-aca-section-1557/</a>.

<sup>18</sup> MaryBeth Musumeci et al., *HHS's Proposed Changes to Non-discrimination Regulations under ACA Section 1557*, Kaiser

<sup>&</sup>lt;sup>18</sup> MaryBeth Musumeci et al., *HHS's Proposed Changes to Non-discrimination Regulations under ACA Section 1557*, Kaiser Family Foundation (Jul. 1, 2019), <a href="https://www.kff.org/disparities-policy/issue-brief/hhss-proposed-changes-to-non-discrimination-regulations-under-aca-section-1557/">https://www.kff.org/disparities-policy/issue-brief/hhss-proposed-changes-to-non-discrimination-regulations-under-aca-section-1557/</a>.