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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

Mr. Roger Severino

Director
Office for Civil Rights
U.S. Department of Health and Human Services
200 Independence Ave. S.W.
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 and Director Severino,

Legal Council for Health Justice (Legal Council) submits the following comments in response to the Department of Health and Human Services' ("HHS", "the 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.

At Legal Council we serve low income individuals, children, and families regardless of their sex, gender identity and expression, sexual orientation, race, national origin, immigration status or language proficiency. We provide specialized free legal services, policy, and other advocacy for those living with chronic, disabling, and stigmatizing health conditions to maximize access to good health, education-supporting them in reaching their full potential. In short, the populations we serve are the very same who will be harmed by the proposed changes to the current, vitally important, rules.

As you are aware, Section 1557 is the key nondiscrimination provision of the Affordable Care Act (ACA).[1] It prohibits discrimination in health programs and activities receiving federal financial assistance, health programs and activities administered by the executive branch, as well as entities created under the ACA, health plans sold through the Marketplaces and the Marketplaces themselves. Section 1557's protections extend to discrimination on the basis of race, color, national origin (including language access), sex, age, and disability by building on existing civil rights laws.[2]

The proposed attempts to change the administrative implementation of Section 1557 poses 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 will create additional barriers for people in these vulnerable groups and lead to worse physical and mental health outcomes throughout our communities.

The proposed rule change has already had a profound impact on the lives of clients like Francesca. Francesca came to the United States from southern Europe over 30 years ago. She worked hard, put down roots, and started a business. While Francesca's business thrived and supported jobs in the community, Francesca had great difficulty in her personal life. Francesca believed that she was born in the wrong body. Francesca (named Francisco at birth) was meant to be a female, felt like a female, and wished to live as her true female-identified self. These feelings and desires were so strong that she contemplated self-mutilation of her male genitalia to make her physical appearance align with her internal female identity. After 30 years of battling depression due gender dysphoria, Francesca, now in her late 60s, finally gained the courage to have gender confirming surgery. Francesca realized that if she did not take these steps, she could no longer survive in a male body. Due to these impending rule changes, Francesca's two years of surgery preparation, which included hormonal therapy, breast augmentation, and psychological counseling, is for naught because her health insurance company has informed Francesca that they will not approve the final surgery until they see whether this proposed rule is finalized. Francesca planned her transition relying on insurance coverage for her whole transition. Francesca's goal is to live authentically and free from gender dysphoria for the last chapter of her life. Francesca's insurance is delaying approval for any gender affirming surgeries as they wait for the outcome of these proposed rules, leaving Francesca in limbo for accessing care they are entitled to under current law.

Legal Council has seen the powerful positive impact Section 1557 and its regulatory protections have on our clients and we *strongly* oppose the proposed elimination or rollback of critical protections guaranteed by Section 1557 of the Affordable Care Act ("ACA") and the 2016

[1] Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (Mar. 23, 2010); 42 U.S.C. § 18116.

[2] Title VI of the Civil Rights Act of 1964 (42 U.S.C. § 2000d et seq.), Title VII of the Civil Rights Act of 1964 (42 U.S.C. § 2000e et seq.), Title IX of the Education Amendments of 1972 (20 U.S.C. § 1681 et seq.), Section 794 of Title 29, or the Age Discrimination Act of 1975 [42 U.S.C. § 6101 et seq.].

Nondiscrimination in Health Programs or Activities final rule ("2016 final rule"). We urge that this NPRM be rescinded in its entirety.

The Proposed Rule Impermissibly Attempts to Narrow the Scope of Section 1557

The 2016 final rule that implemented 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 improperly 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."[3]Additionally, the proposed rule improperly attempts to narrow the 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. 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).

This proposed change is discriminatory and wrong.

If the proposed rule is nevertheless implemented, it would have significant consequences, particularly for consumers who purchase short-term limited duration insurance ("STDLI"). The proposed rule would generally not apply nondiscrimination protections to STDLI plans because insurers would no longer be considered health care entities and these specific plans do not receive federal financial assistance. Legal Council, through the Protect Our Care Illinois Coalition, has worked to fight against STDLI plans generally because of their strong potential to confuse consumers. Loosening discrimination provisions on these plans that already confuse consumers is a step in the wrong direction. Similarly, we have fought age, gender, and disability discrimination in many health plans that were commonplace prior to the ACA and remain an obstacle for health care for millions of Americans. The passage of this rule would embolden plans to shortchange individuals from coverage of essential health needs like maternity care, cancer screenings, and even primary care. Preventing access to care based on gender, age, and disability is not only deplorable in its own right, but ultimately costlier to states as they will likely be forced to address these needs through costly emergency room visits for patients who would have otherwise been covered under the current law.

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[3] 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/.

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 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 that was in the health care industry before the ACA.

The proposed rule further attempts to again open the door foro insurance companies to categorically exclude coverage of gender-affirming care from their plans and deny individuals coverage of procedures used for gender affirmation. Under the proposed rule, transgender, non-binary and gender nonconforming people assigned female at birth whose gender marker is male or non-binary could also be denied coverage for necessary care such as a pap smear or mammogram. Similarly, transgender nonbinary, and gender nonconforming people assigned male at birth whose gender marker is female or nonbinary could be denied coverage for necessary care, such as a prostate exam.

Finally, the proposed rule would have a disproportionate impact on women who are pregnant, particularly women of color. Women of color already face unique barriers to accessing pregnancy-related and/or abortion care such as discrimination, harassment and refusals of care. Women of color experience significantly higher rates of pregnancy-related complications. Black women, for example, are 3-4 times more likely to die from pregnancy related complications than white women. Section 1557 provides critical protections needed to change this trend.

These proposed rule changes are unacceptable and take us back to the dark ages of healthcare. We cannot go back to a world where the law enables discrimination that leads to higher premium rates, diminished care, or loss of access to health insurance based on sex.

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. This change is harmful to no meaningful end and would result in less health care and poorer health outcomes for communities in Illinois and 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 often could not get or afford insurance coverage. Luckily, the passage of the ACA prohibited compliant plans from discriminating against LGBTQ people, ending decades long practices of charging more for pre-existing conditions or denying coverage altogether. However, the proposed rule rolls back this progress, allowing states and health insurance marketplaces to once again discriminate against LGBTQ people in eligibility determinations, enrollment periods, and more. Similarly, agents and brokers who assist with enrollment in marketplace plans could discriminate against LGBTQ people, risking their health and denying them access to entitled care.

Under the proposed rule, Programs of All-Inclusive Care for the Elderly ("PACE") organizations, which serve people ages 55+, could discriminate against LGBTQ people.[4] There are more than 3 million LGBTQ people age 55+ in the U.S. That number is expected to double within the next 20 years.[5] Many older LGBTQ adults already feel reluctant to discuss their sexual orientation and gender identity with health providers due to fear of judgment and/or substandard care.[6] The proposed rule would only further discourage older LGBTQ adults from sharing information that may be relevant to the health services they need.

Approximately 4.3% of the Illinois population identifies as LQBTQ. Of that, 28% have families with children.[7] The proposed changes not only threaten access, but actively incentivize discrimination against the LGBTQ population. Legal Council strongly supports the Illinois Department of Insurance's comments that the proposed rule will undermine civil rights protections for millions of consumers, create an uneven playing field for health insurers, negatively affect state insurance markets, and have a significant negative impact on communities that are already vulnerable to discrimination in health care, housing, and employment.

The rule changes will adversely impact mental health services for people who are LGBTQ. As stated previously, the proposed change will lead to decreased health insurance options and decreased access to high quality physical and mental health services, leading to reduced care and increased discrimination towards LGBTQ individuals. Studies confirm that almost half of people who identify as transgender experience some form of depression and/or anxiety and an estimated 41% have attempted suicide.[8] This compared to rates of only 4.1% depression and 18% anxiety among the general population.[9] A decrease in health care accessibility and options would likely increase an already staggering rate of depression, anxiety, and suicide among our fellow Americans.

The Proposed Rule Impermissibly Attempts to Eliminate Language Access Protections

The proposed rule illegally pulls back on language access protections for people with Limited English Proficiency ("LEP") and those who have LEP family members by proposing to roll back requirements for the inclusion of taglines on significant documents and remote interpreting standards and by proposing to eliminate recommendations that entities develop language access plans.

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4 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/.

5 Robert Espinoza, Servs. & Advocacy for Gay, Lesbian, Bisexual, & Transgender Elders, Out & Visible: The Experiences and Attitudes of Lesbian, Gay, Bisexual, and Transgender Older Adults, Ages 45-75, 5 (2014), https://www.sageusa.org/wp-content/uploads/2018/05/sageusa-out-visible-lgbt-market-research-full-report.pdf.

6 *Id.*

7 UCLA School of Law Williams Institute. LGBTQ Data and Demographics By State. Accessed on August 9, 2019,https://williamsinstitute.law.ucla.edu/visualization/lgbt-stats/?topic=LGBT&area=17#density.

8 Schreiber, Katherine, *Why Transgender People Experience More Mental Health Issues, Psychology Today* (Dec. 6, 2016) https://www.psychologytoday.com/us/blog/the-truth-about-exercise-addiction/201612/why-transgender-people-experience-more-mental-health

9 *Id.*

Discrimination on the basis of English language proficiency creates unequal access to health care and threatens public health generally. Over 25 million Americans have limited English proficiency. An estimated 19 million LEP adults are insured. Unsurprisingly, LEP makes it difficult for many to navigate an already complicated healthcare system, especially when it comes to medical or insurance terminology. Language assistance is necessary for LEP persons to access federally funded healthcare programs, to be healthy, and to keep our communities well.

The proposed rule would have a disproportionate impact on people with LEP who are low income and/or are people of color. The relationship between a doctor and their patient is sacrosanct. The sanctity of this relationship is not reserved for English speaking Americans, and it is threatened when any person cannot access medical services due to language barriers. At Legal Council, we see people who do not speak English who would otherwise not seek medical care without having competent language services. Without the provisions outlined in the 2016 guidance, non-English speakers would likely would have to use a familial translator, usually an English speaking minor child or distant relative. We regularly see people who have not told their children or family about their HIV status or other chronic health condition. A personal decision that should be afforded to anyone regardless of language proficiency. However, this rule change would likely force them to either use their children to relate sensitive health information in a medical appointment or not access healthcare at all. Children would be tasked to translate sensitive, private health information such as their mom's HIV status or the effects of cancer on their father. The revelation of such private health information can be devastating, socially stigmatizing, and in some families or communities even deadly.

We strongly disagree that nondiscrimination notice, taglines and language access plan language in the 2016 Final Rule were not justified by need, were overly burdensome and created inconsistent requirements. The notice requirement is consistent with the long history of civil rights regulations requiring the posting of notice of rights. The notice is not redundant as OCR created the option of using one consolidated civil rights notice to minimize burden on covered entities. In our 30 years of experience working in healthcare we know that without the notice, members of the public will have limited means of knowing that language services and auxiliary aids and services are available, how to request them, what to do if they face discrimination, and their right to file a complaint.

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

Before the ACA, people with serious or chronic health conditions were often denied health insurance coverage or paid higher prices for substandard plans with coverage exclusions. Under the ACA, insurers can no longer charge higher premiums or deny coverage for people with pre-existing conditions. These protections unquestionably save lives. Specifically, 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."[10] The proposed rule improperly attempts to eliminate these prohibitions.

The proposed rule will have a disproportionate impact on LGBTQ people and people of color who live with disabilities or chronic conditions. At Legal Council, we see numerous examples of the adverse impacts of discriminatory health care. One of our clients Trey, a transgender man, experienced constant discrimination at his doctor's office. Because he did not feel heard or listened to, he avoided further medical care. Trey began to have trouble sleeping and had racing thoughts, which adversely affected his job performance. As a result, he was let go by his employer, losing his only source of income. As the world closed in on him, Trey felt more and more out of control. His friends and family tried to connect him to medical care, but his past trauma made him feel unsafe and unwilling to engage in a medical system that had openly diminished and discriminated against his health needs. It was only after hearing a medical provider address transgender health at a community event, that Trey took the plunge and saw a provider who was well-versed in transgender health needs. He was diagnosed with major depression and an overactive thyroid. After the first 30 days of taking his prescriptions, Trey felt like a whole new person. He is now able to work and is going back to school. After being out of care for four years, he is now stable because he received care that met his needs, allowing him to once again support himself and others. Individuals like Trey deserve to feel safe and heard by their medical providers rather than be pushed out of care due to discriminatory practices.

Conclusion

Adopting this proposed rule would result in significant harm for many of our clients from the most underserved populations who already struggle to access health care. The proposed rule will erect barriers to care for the LGBTQ community; people seeking reproductive health care, including pap smear or mammogram services for gender nonconforming and non-binary individuals assigned female sex at birth; 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 but instead to leave the current regulations, as well as subregulatory guidance, in place.

Legal Council is grateful for the opportunity to submit comments on the proposed rule. Please do not hesitate to contact Carrie Chapman, Senior Director of Litigation and Advocacy (cchampan@legalcouncil.org), to provide further information.

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[10] 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/

Sincerely,

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