

United States Senate

WASHINGTON, DC 20510

June 27, 2019

The Honorable Alex M. Azar II
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue SW
Washington, DC 20201

Dear Secretary Azar:

We write in strong opposition to the proposed rollbacks to the regulations implementing Section 1557 of the Affordable Care Act (ACA), which prohibits discrimination on the basis of race, color, sex (including, but not limited to, discrimination on the basis of pregnancy, false pregnancy, termination of pregnancy, or recovery therefrom, childbirth or related medical conditions, sex stereotyping, and gender identity), national origin, age, disability, and language proficiency. No one should have to fear losing or being denied health care because of who they are or the health care decisions they make.

Also known as the Health Care Rights Law, Section 1557 is a groundbreaking civil rights law providing broad protection for communities who historically face discrimination in the provision of health care – making it clear that health care is a civil and human right. However, the Department of Health and Human Services (HHS or the Department) proposed a revision to the current Section 1557 regulations, which would eliminate many of Section 1557's prohibitions against discrimination and provisions aimed at increasing access to care. HHS's efforts to curtail these critical protections are unacceptable, and we therefore seek answers about why the Department responsible for protecting and promoting health care is instead doing the opposite.

With the passage of the ACA in 2010, Congress expanded protections against discrimination for patients in the provision of health care.¹ In December 2016, a federal judge – the same judge who in late 2018 ruled the entire ACA unconstitutional – prohibited enforcement of the Section 1557 provisions that prohibit discrimination on the basis of gender identity or termination of pregnancy.² The Trump Administration declined to appeal the case, instead notifying the court it intended to modify the Section 1557 regulations. On June 13, 2019, the Trump Administration issued its proposed rule that abdicates its responsibility to protect against discrimination on the basis of sex, including adding a religious exemption, and removing protections for gender

¹ 42 U.S. Code § 18116; https://www.federalregister.gov/documents/2016/05/18/2016-11458/nondiscrimination-in-health-programs-and-activities?utm_campaign=subscription+mailing+list&utm_medium=email&utm_source=federalregister.gov

² https://www.aclu.org/sites/default/files/field_document/fa_order.pdf

identity, termination of pregnancy, and Limited English Proficiency (LEP).³ These proposed rollbacks to Section 1557's implementing regulations would harm communities who experience bias accessing health care and would continue the troubling pattern of the Trump Administration's HHS Office for Civil Rights (OCR) taking steps to eliminate protections against discrimination.

The proposed rule attempts to eliminate protections for the LGBTQ community by removing prohibitions against discrimination on the basis of gender identity and sex stereotyping, understood to also include sexual orientation. Transgender, gender nonbinary, and gender nonconforming people face significant barriers to accessing quality, affordable health care. According to the 2015 U.S. Transgender Survey, one-third of transgender survey respondents reported having at least one negative experience related to their gender identity.⁴ Approximately one-fourth of individuals surveyed reported problems with insurance coverage as a result of their gender identity. Approximately 40 percent of transgender people with disabilities were more likely to have one negative experience with health care providers, compared to 30 percent of transgender people who did not identify as having a disability. Many transgender people have reported being misnamed or misgendered throughout hospital stays. Nearly one-quarter of people surveyed did not seek medical treatment out of fear of being mistreated as a transgender person. This proposed rule—predicated on prejudice—would willfully encourage discrimination against transgender people, particularly those with HIV/AIDS, people of color, and people with disabilities. Given the barriers members of the LGBTQ community already face in the health care system, it is unconscionable that HHS would attempt to eliminate protections in existing law.

The proposed Section 1557 regulations could again allow sex discrimination in the health care system. Prior to passage of the ACA, insurance providers often charged women more for their health insurance than men, only 12 percent of plans sold on the individual market covered maternity care, and people could be denied fertility coverage because of their age or marital status.⁵ The new proposed rule now removes provisions prohibiting discrimination on the basis of pregnancy, false pregnancy, termination of pregnancy, or recovery from childbirth and attempts to add a religious exemption to Section 1557's prohibition against sex discrimination. The proposed changes could endanger existing protections for people needing abortions, especially women of color, and transgender, gender nonbinary, and gender nonconforming people, who already face significant barriers to accessing abortion care. The proposed rule's addition of a religious exemption would allow any religiously-affiliated health care entity, including hospitals and insurance companies, to exempt themselves from complying with Section 1557's important protections. This would exacerbate existing problems with providers who already deny health care to people who experience complications with their pregnancy, even in situations where the person's life is threatened.⁶ The proposed rule fails to address whether

³ <https://www.hhs.gov/sites/default/files/1557-nprm-hhs.pdf>

⁴ <https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf>.

⁵ https://nwlc-ciw49tixgw5lbab.stackpathdns.com/wp-content/uploads/2015/08/nwlc_2012_turningofairness_report.pdf.

⁶ <https://nwlc.org/blog/when-the-trump-pence-administration-tries-to-hide-its-efforts-to-roll-back-our-rights-we-dont-back-down/>.

Section 1557 prohibits these forms of sex discrimination – such as a hospital refusing to provide a patient care for a miscarriage or because they have had an abortion.

The proposed rule could undermine protections for people whose primary language is not English, by eliminating the requirement that non-English speakers have access to health care documents in their preferred language. The 2016 Section 1557 regulations require covered entities to inform people with LEP about the availability of language assistance services by providing taglines in “at least the top 15 languages spoken by individuals with LEP” for publications and communications bigger than a postcard or brochure and taglines in “at least the top two languages spoken by individuals with LEP” in smaller publications.⁷ The proposed regulations could eliminate requirements for providing nondiscrimination notices that inform people about their rights to access language services and file complaints of discrimination. These proposed revisions could pose significant harm to people with LEP and especially immigrants, who often face extensive hurdles in communicating their health care decisions and obtaining health care services.⁸ The Department justifies its decision to limit access to available translated and accessible publications by claiming such measures will save money. Yet, cutting critical translated medical publications, especially for the sole purpose of saving money, unfairly singles out people most in need of these critical services to access care and understand their medical decisions.

Finally, the proposed rule will exacerbate barriers to care for people living with disabilities and chronic conditions. Section 1557 provides key protections for people living with disabilities and chronic conditions, and the 2016 regulations require various accommodations for people with disabilities, who often face extreme barriers in accessing health care. The proposed rule could eliminate requirements to post notices of how people can request auxiliary aids and services and materials in alternate formats, leaving people without accessible information about how to enforce their rights.

The federal government should prioritize improving and expanding access to health care, not implementing rules that will lead to more people getting sicker and having less care. We urge you to withdraw the proposed Section 1557 regulations and protect the rights of all people in accessing health care. To help us understand how HHS developed this rule, please respond to the following questions by no later than July 18, 2019:

1. What was the process for developing the proposed rule? Please provide a timeline for the development of the proposed rule.
 - a. Did any outside organizations provide HHS with a draft or outline of the proposed rule? Please provide a complete list of all organizations involved.
 - b. Were the Executive Office of the President of the United States and/or the Office of the Vice President of the United States consulted? If so, which individuals within these offices were consulted? How were they involved?
 - c. Were other federal agencies consulted through the drafting of the proposed rule? If so, which offices and divisions within those agencies were consulted?

⁷ <https://www.law.cornell.edu/cfr/text/45/92.8>.

⁸ <https://www.hhs.gov/sites/default/files/factsheet-section-1557.pdf?language=en>.

2. Given the conflicting court decisions and the December 2016 injunction, patients, issuers, and providers lack clarity regarding their rights and responsibilities under Section 1557.
 - a. What guidance has HHS provided to patients, issuers, and providers to address this uncertainty?
 - b. How has HHS OCR responded to complaints of discrimination on the basis of sex, including sexual orientation and gender identity, since January 20, 2017?
3. What steps are being taken to continue enforcement under Section 1557 of other types of sex discrimination, including sex stereotyping, gender rating, coverage denials, or sexual harassment in health care?
4. What processes are in place to inform people whose complaints conflict with the December 2016 injunction that their complaints will not be investigated? Are these people informed of other means of enforcing their rights?
5. In assessing the cost savings from eliminating requirements for providing information to people with LEP and in accessible forms for people with disabilities, what analyses did the Department conduct to determine whether these changes would result in changes in care, public health costs, or other costs to health providers? Please provide copies of all such assessments. If no analyses were conducted, please explain why.
6. Did HHS consult individuals or organizations that represent people with disabilities or LEP about the potential impact of the changes?

Thank you in advance for your attention to this matter. If you have any questions, or would like to further discuss compliance with this request, please contact Michael Huggins on the Democratic staff for the Committee on Health, Education, Labor and Pensions at (202) 224-0767.

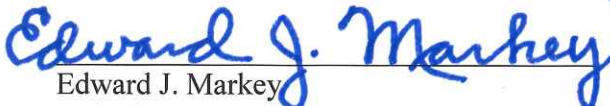
Sincerely,



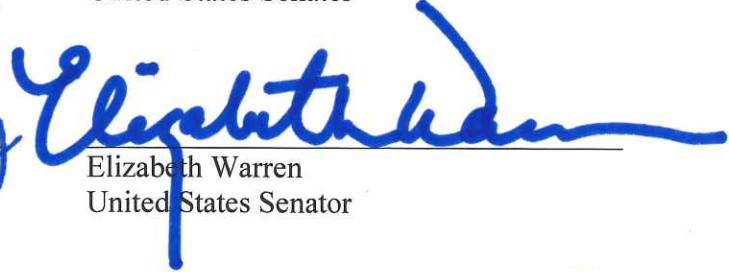
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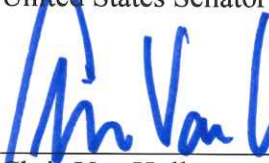

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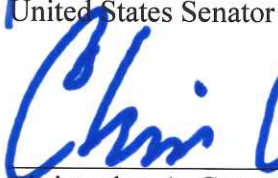

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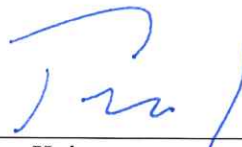

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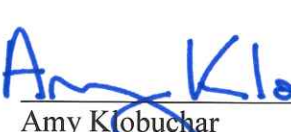

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