



August 13, 2019

Mr. Roger Severino
Director, Office for Civil Rights
U.S. Department of Health and Human Services
200 Independence Ave. SW, Washington, DC 20201

Re: Nondiscrimination in Health and Health Education Programs and Activities (Section 1557 NPRM), RIN 0945-AA11

Dear Mr. Severino:

The National Partnership for Women & Families (National Partnership) represents women and families across the country who are counting on continued implementation of Section 1557 in order to access health care without fear of discrimination.

We thank the Office for Civil Rights (OCR) at the U.S. Department of Health and Human Services (HHS) for the opportunity to comment on the notice of proposed rulemaking (proposed rule) on Section 1557 of the Patient Protection and Affordable Care Act (ACA) ("Health Care Rights Law" or "Section 1557"). **However, we believe the proposed rule undermines the very intent of Section 1557 and strongly urge HHS to rescind the proposed rule in its entirety.**

Section 1557, also known as the Health Care Rights Law, was designed to prohibit discrimination on the basis of race, color, national origin, sex, age, and disability. Section 1557 bans discrimination in health care from entities and programs that receive federal funds, and includes essential civil rights protections for people at the highest risk of harm. Section 1557 provides landmark health protections for women and we strongly oppose any efforts to weaken the law. Our comments, below, delineate how the proposed rule will restrict access to care and further harm already marginalized groups.

Thank you for your consideration. If you have any questions about our comments and recommendations, please contact Debra Ness, president, at dln@nationalpartnership.org or (202) 986-2600.

Sincerely,

A handwritten signature in black ink, appearing to read "Debra Ness", with a long horizontal flourish extending to the right.

Debra L. Ness, President

Overview

The National Partnership strongly opposes the proposed rule for Section 1557 and urges rescinding the proposed rule in its entirety.

The proposed rule would undermine an important civil rights law that has vast public support. The 2016 implementation of the Section 1557 final rule was the product of a rigorous process of deliberation and public input. The rule was developed over the course of six years of study, and following two comment periods, with over 25,000 comments from stakeholders. Stakeholder comments were overwhelmingly supportive of inclusion of protections against discrimination based on sex stereotyping and gender identity, as well as other key nondiscrimination provisions. Adoption of this proposed rule would remove or render ineffective these important safeguards that provide protection and recourse to people who are at highest risk of being harmed by discrimination in health care.

Section 1557 was implemented with the intent to prohibit discrimination based on race, color, national origin, language access, sex (including gender identity, sexual orientation, sex stereotypes, as well as pregnancy, childbirth and related medical conditions), age and disability in:

- Health care;
- Health programs receiving federal assistance;
- Health programs administered by the executive branch; and
- Health plans sold through the marketplaces.

Section 1557 marked the first broad prohibition against sex-based discrimination in health care, and is crucial to ending gender-based discrimination in health care. Sex discrimination in health care is particularly harmful to women of color, LGBTQ people, and people who live at the intersections of multiple identities and therefore suffer compounded discrimination (e.g., a black woman with a disability, or a transgender women living with HIV). 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. The 2016 final rule also protects individuals with limited English proficiency (“LEP”) and individuals with disabilities and/or chronic conditions from discrimination.

The proposed rule’s provisions undermine these protections and would open the door to discrimination.

Below, we offer comments on specific elements of the proposed rule.

1. Limited Applicability

The proposed rule would allow many plans and programs to be exempt from Section 1557 regulations, putting people at risk of discrimination.

We oppose the proposed changes in § 92.1 - 92.3 that would narrow the scope of application of Section 1557. The proposed rule would limit the number of programs subject to Section 1557 and narrow the applicability of Section 1557 protections. The elimination of comprehensive definitions of “covered entities” and “health program or activities” would allow many plans and programs to be exempt from Section 1557 regulations.

Section 1557 applies to any health program or activity that is receiving any amount of federal financial funding or is administered by an Executive Agency or entity established under Title I of the ACA. Thus, Section 1557 applies to all health programs or activities administered by the Department (as well as other federal Departments) plus those established under Title I.

Further, similar to Title VI, Section 1557 applies to all parts of the covered entity, not only the portion receiving federal financial assistance. In addition, given that the majority of individuals access health care through insurance plans, the provision of health insurance is a “health program or activity,” and thus Section 1557 applies to it. This rule’s proposed changes run counter to the statutory text and intent of Section 1557 and would severely limit its application.

Limiting and narrowing the scope of Section 1557 protections will cause people who are already marginalized to be subject to further discrimination and delay seeking necessary care. The ACA and Section 1557 were implemented to expand access to health care and helped to protect many marginalized groups. Many people depend on Section 1557 to protect their right to access health care that does not harm them.

We strongly recommend maintaining the applicability of Section 1557 as laid out in the 2016 final rule.

2. Short-Term Limited Duration (STLDI) Plans

The proposed rule detrimentally would narrow the applicability of Section 1557 for health insurance products and allow discriminatory practices by STLDI plans.

Under the proposed rule, Section 1557 would not apply to certain health insurance plans, such as short-term limited duration insurance (“STLDI”) plans because these insurance providers would no longer be considered health care entities, and these specific plans also do not receive federal financial assistance. This change would have severe consequences, particularly since the administration has expanded the availability of these short-term plans, and consequently, a greater number of consumers are purchasing these plans while mistakenly believing that they are as comprehensive as ACA-compliant plans.¹

¹ Corlette, S., Lucia, K., Palanker, D., & Hoppe, O. (2019, January). *The Marketing of Short-Term Health Plans*. Retrieved 8 August 2019 <https://www.rwjf.org/en/library/research/2019/01/the-marketing-of-short-term-health-plans.html>

Short-term plans are notorious for discriminating against consumers based on gender, age, and disability. If implemented, this proposed rule would be especially harmful to women, particularly women with low incomes whose economic security is most threatened, and women who could face intersectional discrimination (e.g., women of color). The proposed rule would allow 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 pre-existing conditions unique to women like breast or cervical cancer. For example, a 2018 study found that none of the existing short-term plans covered maternity care.² Short-term plans also discriminate based on gender identity by excluding coverage for transition-related services, such as surgery. These plans are also not subject to mental health parity, which puts women, who experience depression at roughly twice the rate of men, at greater risk of not receiving adequate care.³ Additionally, the proposed rule would unfairly allow short-term health plans to 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.⁴

We strongly recommend keeping the existing rule's definition of covered entities, which includes all health plans offered by an issuer that receives federal funding. This broader application will ensure that the greatest number of women and families do not face discriminatory practices of STLDI plans.

3. Benefit Design and Marketing

The proposed rule would eliminate provisions protecting women and families from discriminatory marketing and benefit design practices.

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.

These policies were particularly harmful for women, and especially women of color, who experience higher rates of chronic illness that could be categorized as a preexisting condition due to systemic barriers to health care. Furthermore, women of color have higher mortality rates than white women for many conditions. For example:

- African American women are twice as likely to develop diabetes as white women.⁵¹

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

³ Harvard Medical School. (2011, May). *Women and Depression*. Retrieved 8 August 2019 from <https://www.health.harvard.edu/womens-health/women-and-depression>

⁴ Lueck, S. (2018, September). Key Flaws of Short-Term Health Plans Pose Risks to Consumers. Retrieved 8 August 2019 from https://www.cbpp.org/research/health/key-flaws-of-short-term-health-plans-pose-risks-to-consumers#_ftn10

⁵ Office on Women's Health. (2016, July 13). *Diabetes and African Americans*. U.S. Department of Health and Human Services. Retrieved 10 May 2017, from <https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=4&lvlid=18>

- Black women have 14 percent higher cancer death rates than non-Hispanic white women, despite a six percent lower incidence rate.⁶¹
- Hispanic women are twice as likely to develop diabetes as white women.⁷¹
 - Diabetes affects more than one in ten Hispanics. Among Hispanic women, diabetes affects Mexican-Americans and Puerto Ricans most often.⁸¹
- Compared to non-Hispanic whites, cervical cancer incidence rates are 44 percent higher for Latinas, and liver and stomach cancer incidence rates are about twice as high.⁹¹
- Other health conditions, like the Hepatitis B virus (HBV), were also considered preexisting conditions prior to the ACA.¹⁰¹
 - Chronic HBV affects about 1.3 million people in the United States, and Asian American and Pacific Islanders (AAPIs) account for over half of the chronic HBV cases and resulting deaths.¹¹¹ AAPI women are 20 percent more likely to die from viral hepatitis as compared to non-Hispanic whites.¹²¹

Under the ACA, insurers can no longer charge higher premiums or deny coverage for people with pre-existing conditions. 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.¹³ 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."¹⁴ The proposed rule improperly attempts to eliminate these prohibitions.

We urge HHS to maintain the protections laid out in the ACA and Section 1557 related to benefit design and marketing.

4. Discrimination against People with Disabilities

⁶ American Cancer Society Inc. (2016). *Cancer Facts and Figures 2016*. Retrieved 10 May 2017, from <http://www.cancer.org/acs/groups/content/@research/documents/document/acspc-047079.pdf>

⁷ Office on Women's Health. (2017, June 12). *Diabetes: Do women of color need to worry about diabetes?* U.S. Department of Health and Human Services. Retrieved 19 September 2017, from <https://www.womenshealth.gov/a-z-topics/diabetes>

⁸ Ibid.

⁹ American Cancer Society Inc. (2016). *Cancer Facts and Figures 2016*. Retrieved 10 May 2017, from <http://www.cancer.org/acs/groups/content/@research/documents/document/acspc-047079.pdf>

¹⁰ Gordon, E. (2017, April 15). *U.S. Health Care Wrestles With the 'Pre-Existing Condition.'* National Public Radio. Retrieved 10 May 2016, from <http://www.npr.org/sections/health-shots/2017/04/15/523577871/u-s-health-care-wrestles-with-the-pre-existing-condition>

¹¹ Do, T.N., & Nam, S. (2014, August 20). *Knowledge, Awareness and Medical Practice of Asian Americans/Pacific Islanders on Chronic Hepatitis B Infection*. *Pogon Sahoe Yongu* 31(3): 341-364. Retrieved 10 May 2017, from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4139091/pdf/nihms440000.pdf>

¹² Kochanek, K., Murphy, S. et al. (2016, June 30). *National Vital Statistics Reports: Deaths: Final Data for 2014*. Centers for Disease Control and Prevention. 65(4): 1-122. Retrieved 15 May 2017, from https://www.cdc.gov/nchs/data/nvsr/nvsr65/nvsr65_04.pdf

¹³ MaryBeth Musumeci et al., *HHS's Proposed Changes to Non-discrimination Regulations under ACA Section 1557*, Kaiser Family Foundation. Retrieved 1 June 2019, from <https://www.kff.org/disparities-policy/issue-brief/hhss-proposed-changes-to-non-discrimination-regulations-under-aca-section-1557/>

¹⁴ Ibid.

The proposed rule seeks to exempt certain entities from providing important services and aids to people with disabilities.

We strongly disagree with the provision to exempt entities smaller than 15 people from the requirement to provide auxiliary services and aids to people with disabilities. This prevents those with disabilities from receiving the services they need from these entities. In addition, we oppose the narrowing of the definition of facilities that are required to provide accessibility accommodations and exempting institutions from accessibility requirements in the case of “undue hardship”. This provision once again restricts those with disabilities from accessing areas, services and institutions that may be integral to their survival or well-being. The concept of “undue hardship” also introduces a gray area that can potentially make it easier for entities to eliminate accessibility services. People living with disabilities are already discriminated against and these proposed changes would worsen this discrimination.

In addition, people with disabilities may delay seeking care because of difficulty communicating (if no aide is present) or lack of accessibility services. In limiting the provisions that support those with disabilities, an undue burden is placed on these individuals to find alternative methods of transportation, communication and accommodation. These changes could have severe impacts on the health of people living with disabilities and could also place undue financial burden on them as they may be forced to pay for these auxiliary services themselves.

We strongly recommend maintaining Section 1557’s requirements for support and services for people with disabilities.

5. Protections against Discrimination based on Gender, Sexual Orientation and Sex Stereotyping

The proposed rule will threaten LGBTQ people’s access to necessary health care and coverage.

- a) *The proposed rule’s interpretation of Title IX and its definition of “sex” is improperly narrow and inconsistent with precedent.*

The proposed rule would define “sex” narrowly to exclude protections against discrimination based on sex stereotyping and gender identity – this reading is both improper and inconsistent with precedent. In 2016 HHS concluded that there was overwhelming support for including protections from discrimination based on sex stereotyping and gender identity. The 2016 final rule reflects this consensus.

Not only does the proposed rule ignore that conclusion, but it also contradicts over 20 years of federal case law – and clear Supreme Court precedent. The overwhelming majority of courts that have been presented with the question of whether federal sex discrimination laws such as Section 1557 specifically cover anti-transgender discrimination have firmly ruled that they do. While the proposed rule does correctly note that a case defining “sex” for purposes of Title VII is currently pending before the U.S. Supreme Court, that litigation

is not a reason for this regulation to move forward as proposed but is instead a reason for HHS to delay rulemaking on this question. At a minimum, HHS should reopen this rule for additional comments following the Supreme Court decision in that case.

In this rule, HHS is also proposing to roll back explicit and long-standing protections based on sexual orientation and gender identity in other, unrelated regulations. It is inappropriate for this rulemaking to be combined, as these other regulations are entirely unrelated to Section 1557 of the Affordable Care Act and are outside the jurisdiction of OCR. It is particularly arbitrary and capricious for HHS to characterize these as “conforming amendments” without offering any legal, policy or cost-benefit analysis or justification about the impact these regulations have had – some of which have been in place for over a decade – or the effects that rolling them back now would have on individuals or other government programs.

While the administration does not have the power to change the statutory protections in place under Section 1557 — only Congress does — the proposed rule will sow confusion and will discourage patients from seeking health care in the first place, or from speaking up if they experience discrimination.

We urge HHS to maintain the protections laid out in the ACA and Section 1557 related to protections from discrimination based on sex stereotyping and gender identity.

b) LGBTQ people already face significant harassment and discrimination when accessing health care

Transgender and nonbinary people already experience high rates of discrimination and harassment in health care. Thirty-three percent report that they had at least one negative experience in a health care setting relating to their gender identity in the past year.¹⁵ These rates were even higher for Native respondents (50 percent), Middle Eastern respondents (40 percent), multiracial respondents (38 percent) and respondents with disabilities (42 percent).¹⁶ Thirty percent of transgender and nonbinary people also report experiencing unwanted physical contact, such as fondling, sexual assault, or rape, from a provider.¹⁷

Similarly, many people who identify as lesbian, gay, bisexual and queer also report experiencing rampant discrimination and harassment in health care settings.¹⁸ Eight percent report that a doctor or other health care provider refused to see them because of their actual or perceived sexual orientation, and nine percent said a doctor or other health

¹⁵ James, S., Herman, J., Kankin, S., Keisling, M., Mottet, L., & Anafi, M. (2016, December), *Report of the 2015 U.S. Transgender Survey* (pp. 96-97). Retrieved 22 July 2019 from National Center for Transgender Equality website: <https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf>.

¹⁶ James, S., Herman, J., Kankin, S., Keisling, M., Mottet, L., & Anafi, M. (2016, December), *Report of the 2015 U.S. Transgender Survey* (pp. 96-97). Retrieved 22 July 2019 from National Center for Transgender Equality website: <https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf>.

¹⁷ Mirza, S., & Rooney, C. (2018, January 18). *Discrimination Prevents LGBTQ People from Accessing Health Care*. Center for American Progress. Retrieved 22 July 2019, from <https://www.americanprogress.org/issues/lgbt/news/2018/01/18/445130/discrimination-prevents-lgbtq-people-accessing-health-care/>.

¹⁸ Ibid.

care provider used harsh or abusive language when treating them.¹⁹ Additionally, seven percent report that a provider has refused to recognize their family, including a child or a spouse or partner.²⁰

As a result of this discrimination and harassment, many members of the LGBTQ community avoid seeking necessary, life-saving health care. Eight percent of all LGBTQ people – and 14 percent of those who had experienced discrimination on the basis of their sexual orientation or gender identity in the past year – avoided or postponed needed medical care because of disrespect or discrimination from health care staff.²¹ Among transgender people specifically, 22 percent reported such avoidance.²²

b) The ACA's protections, as implemented by the 2016 final rule, remain critical for addressing the well-documented health disparities facing LGBTQ people.

Section 1557 of the ACA and the 2016 final rule provided many LGBTQ people with meaningful health care options where they previously had few or none at all. It helped address the pervasive discrimination LGBTQ people often face in health care and coverage and made it possible for people in the LGBTQ community to access essential care.²³

The 2016 final rule clarified that Section 1557's prohibition on sex discrimination includes a prohibition of discrimination on the basis of sexual orientation and/or gender identity, including transgender or nonbinary status. It also made clear that health care providers cannot refuse to treat someone because of their gender identity and/or sexual orientation. The 2016 final rule is sound policy that has been critical for LGBTQ patients to access the care that they need – it has promoted equal access to medically necessary health services and reduced discrimination against the LGBTQ community.

Moreover, under the 2016 final rule, insurance companies could not categorically exclude or deny coverage for LGBTQ people or for gender-affirming care. In addition, 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 sex assigned at birth, gender identity or gender on a medical or health insurance plan record differs from the one to which such health services are ordinarily or exclusively available.

c) The proposed rule threatens LGBTQ patients' access to health care and coverage by sowing confusion and putting LGBTQ people at risk of increased discrimination and harassment.

¹⁹ Ibid.

²⁰ Ibid.

²¹ Ibid.

²² Ibid.

²³ Baker, K., & Durso, L. (2017, March 22). *Why Repealing the Affordable Care Act Is Bad Medicine for LGBTQ Communities*. Center for American Progress. Retrieved 22 July 2019, from <https://www.americanprogress.org/issues/lgbt/news/2017/03/22/428970/repealing-affordable-care-act-bad-medicine-lgbt-communities/>;

Gruberg, S., & Bewkes, F. (2018, March 7). *The ACA's LGBTQ Nondiscrimination Regulations Prove Crucial*. Center for American Progress. Retrieved 22 July 2019, from <https://www.americanprogress.org/issues/lgbt/reports/2018/03/07/447414/acas-lgbtq-nondiscrimination-regulations-prove-crucial/>

All people should receive health care that is free of discrimination, shame, stigma and bias. However, the proposed rule attempts to roll back the rights of the LGBTQ community by erasing all reference to the ACA's protections against discrimination on the basis of sexual orientation and gender identity.²⁴ If enacted, this proposed rule will undoubtedly harm the health and threaten the lives of the LGBTQ community.

The proposed rule could open the door for health care providers to discriminate against or flatly refuse to treat someone because of their gender identity or sexual orientation. In effect, a doctor could refuse to treat a transgender person for a cold or a broken bone, simply because of their gender identity; or a nurse could turn away a bisexual person from an emergency room because of their sexual orientation. Greenlighting discrimination and harassment is unacceptable and will undoubtedly harm the health of the LGBTQ community.

The proposed rule could also lead 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 – without it, the health of the LGBTQ community suffers.²⁵ The proposed rule could, in effect, also allow providers and insurers to refuse to provide and cover certain health care for transgender and nonbinary people. For example, a transgender man could be denied coverage of cervical cancer treatment because of his gender identity.

We strongly urge HHS to uphold Section 1557's protections against discrimination based on gender, sexual orientation and sex stereotyping

6. Access to Abortion Care, Miscarriage Management Care and Other Reproductive Health Care

The proposed rule's unlawful attempt to incorporate Title IX's "Danforth Amendment" threatens the health and well-being of millions of individuals.

a) Abortion is an essential part of health care and a basic human right.

Nearly one in four women in the United States will have an abortion by age 45.²⁶ Access to abortion care facilitates people's autonomy, dignity and ability to make decisions about their bodies, their lives and their futures. It also enables people to adequately care for themselves and their families, and to fully contribute to American society. In short, abortion is fundamental to women's equality, and all people deserve access to abortion care and to comprehensive reproductive health care.

²⁴ Nondiscrimination in Health and Health Education or Activities, 84 Fed. Reg. 27846 (proposed June 14, 2019).

²⁵ Gibson, C. & Huang, P. (2019, June). *Medicaid as an LGBTQ Reproductive Justice Issue: A Primer, Gender-affirming Care in Medicaid* (p. 1). Retrieved 22 July 2019 from National Health Law Program website: <https://healthlaw.org/resource/medicaid-as-an-lgbtq-reproductive-justice-issue-a-primer/>.

²⁶ Guttmacher Institute. (2017, October). *Abortion is a common experience for U.S. women, despite dramatic declines in rates*. [News release]. Retrieved 22 July 2019, from <https://www.guttmacher.org/news-release/2017/abortion-common-experience-us-women-despite-dramatic-declines-rates>

The proposed rule seeks to unlawfully incorporate Title IX’s “Danforth Amendment,” which carves out abortion care and coverage from the ban on discrimination on the basis of sex in the education context. Congress did not include this Title IX language, either explicitly or by reference, in Section 1557. The proposed rule’s effort to incorporate the Danforth Amendment into the Health Care Rights Law, the Affordable Care Act, and the health care system writ large is yet another attempt by this administration to inappropriately treat abortion differently from all other health services and reinforce harmful stigma surrounding abortion care. Additionally, while HHS acknowledges that Section 1557 prohibits discrimination on the basis of termination of pregnancy, it 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. This could embolden individuals and entities in the health care system to discriminate against people who have had abortions and to refuse to provide abortion or other reproductive health care services, and risks having a significant detrimental impact on the health, well-being and economic security of millions of people and families.

- b) *The proposed rule’s effort to prevent access to abortion care undermines the quality of health care that people receive and negatively impacts the economic security of individuals and families.*

The non-partisan National Academies of Science, Engineering, and Medicine (NASEM) recently reaffirmed that abortion care in the United States is safe and effective health care.²⁷ At the same time, NASEM found that the greatest threat to the quality of care comes from politically-motivated laws and regulations that “limit the number of available providers, misinform women of the risks of the procedures they are considering, overrule women’s and clinicians’ medical decision making, or require medically unnecessary services and delays in care.”²⁸ By encouraging providers to deny abortion care, this proposed rule threatens to be another such regulation that makes it more difficult for millions of Americans to access safe, quality care.

When people seek abortion care and are denied, the consequences can be significant. For example, according to a longitudinal study that is frequently cited in peer-reviewed journals, women denied abortion care are more likely to experience eclampsia, death, and other serious medical complications during the end of pregnancy; more likely to remain in relationships where interpersonal violence is present; and more likely to suffer anxiety.²⁹ In addition, research has found that a woman who seeks but is denied abortion care is more

²⁷ National Academies of Sciences, Engineering, and Medicine. (2018). *The Safety and Quality of Abortion Care in the United States*. Retrieved 22 July 2019, from <https://www.nap.edu/24950>

²⁸ National Academies of Sciences, Engineering, and Medicine. (2018). *The Safety and Quality of Abortion Care in the United States* (p. S-10). Retrieved 22 July 2019, from <https://www.nap.edu/24950>

²⁹ Advancing New Standards in Reproductive Health: University of California San Francisco. (2018). *Turnaway Study*. Retrieved 22 July 2019, from <https://www.ansirh.org/research/turnaway-study>

likely to fall into poverty than a woman who is able to get the care she needs.³⁰ The majority of women who seek abortion care already have children, and research demonstrates that there are measurable positive differences in the development and economic well-being of children whose mothers are able to access an abortion as compared to those denied abortion care.³¹

Limiting access to abortion care has a disproportionate impact on people of color and LGBTQ people. Black women account for 27.1 percent of all U.S. abortions, although they make up just 14.9 percent of the U.S. female population.³² Eighteen percent of Latinas will need abortion care over their lifetime, compared to only 10 percent of their white counterparts. AAPI women account for roughly six percent of abortion patients, with disproportionate numbers of AAPI foreign-born women experiencing higher rates of abortion: of foreign-born patients, 20 percent are Asian. Various factors, such as women of color's greater likelihood of being poor, unemployed, or working in low-wage jobs without employer-provided insurance coverage, drive these disproportionate and inequitable abortion rates.

LGBTQ people also rely on a full range of health services, including abortion, to be their whole selves. Despite misconceptions held by policymakers and health care providers, lesbian and bisexual women require sexual and reproductive health services similar to those needed by heterosexual women. A majority of lesbian and bisexual women have reported having had intercourse with men, at least 30 percent have been pregnant,³³ and 16 percent reported one or more abortions.³⁴ Broadly, studies indicate that unintended pregnancies are equally as common, if not more common, for lesbian and bisexual women as for heterosexual women.³⁵ Transgender men, non-binary and gender non-conforming people also need and deserve access to abortion care. Because this rule proposes to remove protections against discrimination on the basis of sexual orientation and gender identity alongside permitting denials of abortion care, we can reasonably anticipate that LGBTQ will doubly face barriers when trying to access reproductive health care; this rule will only compound the harms experienced by LGBTQ people.

³⁰ Foster, D., Roberts, S.C., & Mauldon, J. (2012, October). *Socioeconomic consequences of abortion compared to unwanted birth*. Paper session presented at the American Public Health Associations annual meeting, from <https://apha.confex.com/apha/140am/webprogram/Paper263858.html>

³¹ Foster, D., Raifman, S., Gipson, J., Rocca, C., Biggs, M. (2019, February). Effects of carrying an unwanted pregnancy to term on women's existing children (p. 183). *Journal of Pediatrics*, 205, 183-189; Foster, D., Biggs, M., Raifman, S., Gipson, J., Kimport, K., & Rocca, C. (2018, November). Comparison of health, development, maternal bonding, and poverty among children born after denial of abortion vs. after pregnancies subsequent to an abortion. *Journal of the American Medical Association*, 172(11), 1053-1060.

³² Jerman, J., Jones, R. & Onda, T. (2016, May) *Characteristics of U.S. Abortion Patients in 2014 and Changes Since 2008* (p. 6). Retrieved 22 July 2019 from Guttmacher Institute website: <https://www.guttmacher.org/report/characteristics-us-abortion-patients-2014>

³³ Marrazzo, J., & Stine, K. (2004, June). Reproductive health history of lesbians: Implications for care. *American Journal of Obstetrics and Gynecology*, 190(5), 1298-1304.

³⁴ Saewyc, E., Bearinger, L., Blum, R., & Resnick, M. (1999). Sexual intercourse, abuse and pregnancy among adolescent women: does sexual orientation make a difference? *Family Planning Perspectives*, 31(3), 127-131.

³⁵ Hartnett, C., Lindley, L., & Walsemann, K. (2017). Congruence across sexual orientation dimensions and risk for unintended pregnancy among adult U.S. women. *Women's Health Issues Journal*, 27(2), 145-151.

- c) *The proposed rule also opens the door to discrimination based on someone’s previous reproductive health care decisions and creates harmful stigma around reproductive health care.*

By encouraging providers to discriminate against patients on the basis of their reproductive health decisions, this rule could mean that people could be cut off from a whole range of critical health care services – including routine physicals, cancer treatment or diabetes management – simply because they previously had an abortion. Such discrimination is fundamentally incongruous with medical ethics and significantly undermines the basic health of individuals and communities.

In addition, even when individual patients are not discriminated against or denied services, the stigma created by this rule will have a significant chilling effect on people’s ability to access care. For example, research indicates that two out of three women having abortions anticipate stigma if others were to learn about it.³⁶ When women feel that abortion is stigmatized, they are more likely to report negative mental health outcomes; conversely, women who perceive community support for the right to terminate a pregnancy are less likely to feel guilt and shame.³⁷ Research also suggests that abortion stigma can have economic costs for women.³⁸

We strongly urge maintaining the existing regulatory provisions implementing Section 1557, which would help protect access to abortion care for all people.

7. Religious Exemptions and Refusals of Care

The proposed rule dramatically expands religious refusals of care, resulting in lack of access to health care and harm to millions of people.

The proposed rule attempts to incorporate a broad religious exemption into Section 1557’s protections against discrimination on the basis of sex. This exemption is contrary to the express purpose of Section 1557 and violates the plain language of the statute. Furthermore, the 2016 final rule intentionally did not include any religious exemptions because certain protections for providers’ religious beliefs already exist elsewhere in law and would not be displaced by Section 1557. However, this proposed rule’s dramatic expansion of religious exemptions significantly increases the risk that our nation’s most vulnerable communities will be denied access to basic, needed health care services.

Like the final “health care conscience rule” issued by HHS in May 2019, this proposed rule would improperly permit health care entities and workers to refuse to provide services to patients if those actions go against their religious or moral beliefs, prioritizing the beliefs of a few over the right to health care for many. In particular, this proposed rule would open

³⁶ Norris, A., Bessett, D., Steinberg, J., Kavanaugh, M., Zordo, S., & Becker, D. (2011). Abortion stigma: a reconceptualization of constituents, causes, and consequences (p. S50). *Women’s Health Issues*, 21(3), S49-54.

³⁷ *Ibid.*

³⁸ *Ibid.*

the door for discrimination against LGBTQ people and people seeking reproductive health care.

- a) *Religious refusals of care cause disproportionate harm to women, LGBTQ people, people, of color, and people living in rural areas of the country.*

Already, across the country, refusals of care based on personal beliefs have been invoked in countless ways to deny patients the care they need. For example, one woman experiencing pregnancy complications rushed to the only hospital in her community, a religiously affiliated facility, only to be denied the miscarriage management she needed because the hospital objected to this care.³⁹ Another woman experiencing pregnancy loss was denied care for 10 days at a religiously affiliated hospital outside Chicago, Illinois.⁴⁰ A patient in Arkansas endured a number of dangerous pregnancy complications and could not risk becoming pregnant again; she requested a sterilization procedure at the time of her cesarean delivery, but her Catholic hospital provider refused to give her the procedure.⁴¹ Yet another woman was sent home by a religiously affiliated hospital with two Tylenol after her water broke at 18 weeks of pregnancy. Although she returned to the hospital twice in the following days, the hospital did not give her full information about her condition and treatment options.⁴²

In addition, religious refusals disproportionately harm LGBTQ people, especially those who are transgender, nonbinary, or gender nonconforming. LGBTQ people are often refused health care services because of their sexual orientation and/or gender identity.⁴³ According to one study, eight percent of LGBTQ people were refused healthcare because of their sexual orientation and 29 percent of transgender people were refused healthcare because of their gender identity. Twelve percent of transgender people also were specifically refused gender-affirming health care.⁴⁴ When LGBTQ people are refused treatment, it becomes difficult or impossible to find another provider, especially for transgender people and those living in rural areas. In one study, 18 percent of LGBTQ people said if they were turned

³⁹ Shepard, K., Platt, E., Franke, K., & Boylan, E. (2018). *Bearing Faith: The Limits of Catholic Health Care for Women of Color* (p. 6). Retrieved 22 July 2019 from Public Rights Private Conscience Project – Columbia Law website: <https://www.law.columbia.edu/sites/default/files/microsites/gender-sexuality/PRPCP/bearingfaith.pdf>

⁴⁰ Kaye, J., Amiri, B., Melling, L., & Dalven, J. (2016). *Health Care Denied: Patients and Physicians Speak Out About Catholic Hospitals and the Threat to Women's Health and Lives* (p. 12). Retrieved 22 July 2019 from American Civil Liberties Union website:

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

⁴¹ National Women's Law Center. (2017, April). *The Patient Should Come First: Refusals to Provide Reproductive Health Care* (p. 1). Retrieved 22 July 2019, from <https://nwlc-ciw49tixgw5lbab.stackpathdns.com/wp-content/uploads/2017/05/Refusals-FS.pdf>;

Somashekhar, S. (2015, September 13). A Pregnant Woman Wanted Her Rubes Tied. Her Catholic Hospital Said No. *Washington Post*. Retrieved 22 July 2019, from https://www.washingtonpost.com/national/a-pregnant-woman-wanted-her-tubes-tied-her-catholic-hospital-said-no/2015/09/13/bd2038ca-57ef-11e5-8bb1-b488d231bba2_story.html?utm_term=.49172f7536e1

⁴² Shepard, K., Platt, E., Franke, K., & Boylan, E. (2018). *Bearing Faith: The Limits of Catholic Health Care for Women of Color* (p. 27). Retrieved 22 July 2019 from Public Rights Private Conscience Project – Columbia Law website: <https://www.law.columbia.edu/sites/default/files/microsites/gender-sexuality/PRPCP/bearingfaith.pdf>

⁴³ Mirza, S., & Rooney, C. (2018, January 18). *Discrimination Prevents LGBTQ People from Accessing Health Care*. Center for American Progress. Retrieved 22 July 2019, from <https://www.americanprogress.org/issues/lgbt/news/2018/01/18/445130/discrimination-prevents-lgbtq-people-accessing-health-care/>.

⁴⁴ Ibid.

away, it would be very difficult or not possible to find the same type of service at a different hospital or clinic. For transgender people specifically, 30 percent said it would be difficult or not possible for them to find the same service somewhere else if they were refused care. Rates are even higher for LGBTQ people living outside of a metropolitan area: 41 percent said if they were turned away, it would be very difficult or not possible to find the same type of service at a different hospital; 31 percent said it would be very difficult or not possible to find the same type of service at a different clinic.⁴⁵

Expanding religious refusals in the way contemplated by this rule would also have a disproportionate impact on people of color and people living in rural areas of the country, further reducing their access to quality health care. For example, new research shows that women of color in many states disproportionately receive their care at Catholic hospitals. In 19 states, women of color are more likely than white women to give birth in Catholic hospitals.⁴⁶ These hospitals as well as many Catholic-affiliated hospitals must follow the Ethical and Religious Directives (“ERDs”), which provide guidance on a wide range of hospital matters, including reproductive health care, and can prevent providers from offering the standard of care.⁴⁷ Providers in one 2008 study disclosed that they could not provide the medical standard of care for managing miscarriages at Catholic hospitals, and as a result, women were delayed care or transferred to other facilities at great risk to their health.⁴⁸ The reach of this type of religious refusal of care is growing with the proliferation of both the types of entities using religious affiliation to discriminate and the number of religiously affiliated entities that provide health care and related services.⁴⁹ In communities that have experienced historic and ongoing coercion within the medical system, the proposed rule could further undermine the trust that is the foundation of the patient-provider relationship and deepen health disparities.

In rural areas, people often have to travel long distances to reach health care providers, and lack of public transportation and weakened infrastructure can make it even more difficult for people to get to even those providers that are somewhat accessible. If people are then refused care because of a provider’s religious beliefs, there may be no other sources of health or life-preserving medical care.⁵⁰

⁴⁵ Mirza, S., & Rooney, C. (2018, January 18). *Discrimination Prevents LGBTQ People from Accessing Health Care*. Center for American Progress. Retrieved 22 July 2019, from <https://www.americanprogress.org/issues/lgbt/news/2018/01/18/445130/discrimination-prevents-lgbtq-people-accessing-health-care/>.

⁴⁶ Shepard, K., Platt, E., Franke, K., & Boylan, E. (2018). *Bearing Faith: The Limits of Catholic Health Care for Women of Color* (p. 5). Retrieved 22 July 2019 from Public Rights Private Conscience Project – Columbia Law website: <https://www.law.columbia.edu/sites/default/files/microsites/gender-sexuality/PRPCP/bearingfaith.pdf>

⁴⁷ Shepard, K., Platt, E., Franke, K., & Boylan, E. (2018). *Bearing Faith: The Limits of Catholic Health Care for Women of Color* (p. 8). Retrieved 22 July 2019 from Public Rights Private Conscience Project – Columbia Law website: <https://www.law.columbia.edu/sites/default/files/microsites/gender-sexuality/PRPCP/bearingfaith.pdf>

⁴⁸ Freeman, L. (2008, October). When there’s a heartbeat: miscarriage management in catholic-owned hospitals (p. 1777). *American Journal of Public Health*, 98(10), 1774-1778.

⁴⁹ See, e.g., Uttley, L., Reynerston, S., Kenny, L., & Melling, L. (2013). *Miscarriage of Medicine: the Growth of Catholic Hospitals and the Threat to Reproductive Health Care*. Retrieved 22 July 2019 from American Civil Liberties Union website: <https://www.aclu.org/files/assets/growth-of-catholic-hospitals-2013.pdf>.

⁵⁰ Since 2010, eighty-three rural hospitals have closed. See The Cecil G. Sheps Center for Health Services Research. (n.d.). *Rural Hospital Closures: January 2010 – Present*. Retrieved 22 July 2019, from <http://www.shepscenter.unc.edu/programs-projects/rural-health/rural-hospital-closures/>

The sweeping religious refusals of care permitted under this rule would significantly increase the harm to patients and people seeking access to health care in a variety of context and settings, with devastating consequences to people's health and lives.

b) Religious refusals of care are contrary to medical ethics, undermine informed consent and interfere in the patient-provider relationship.

The proposed rule also disregards medical ethics and standards of care established by the medical community by allowing providers to opt out of providing medical care. Medical practice guidelines and standards of care establish the boundaries of medical services that patients can expect to receive and that providers should be expected to deliver. Yet, the proposed rule's religious exemption seeks to allow providers and institutions to ignore the standards of care, particularly surrounding reproductive and sexual health, as well as gender-affirming care. Information, counseling, referral and provision of contraceptive and abortion services are part of the standard of care for a range of common medical conditions, including heart disease, diabetes, epilepsy, lupus, obesity and cancer.⁵¹ Gender-affirming care is also medically indicated in a variety of circumstances. Individuals seeking reproductive health care, regardless of their reasons for needing these services, should be treated with dignity and respect. Allowing providers refuse to provide such care based on their personal religious beliefs flouts established medical guidelines and ethics.

Religious exemptions also threaten informed consent, insofar as they permit providers to withhold pieces of information about available health care services or care options from patients. Informed consent is a foundational principle of medical ethics and requires that providers disclose relevant and medically accurate information about treatment choices and alternatives so that patients can competently and voluntarily make decisions about their medical treatment or refuse treatment altogether.⁵² By allowing providers, including hospitals and health care institutions, to refuse to provide patients with information, the proposed rule makes it impossible for patients to have full information regarding treatment options. Not only does this compromise the quality of care that patients receive, it also

⁵¹ For example, the American College of Obstetricians and Gynecologists (ACOG) and the American Academy of Pediatrics guidelines state that the risks to the woman from persistent severe pre-eclampsia are such that delivery (abortion) is usually suggested regardless of fetal age or potential for survival. AM. ACAD. OF PEDIATRICS & AM. COLL. OF OBSTETRICIANS AND GYNECOLOGISTS, GUIDELINES FOR PERINATAL CARE 232 (7th ed. 2012).

⁵² See, e.g., Committee on Ethics, American College of Obstetricians and Gynecologists. (2009, August; reaffirmed 2015). *Committee Opinion No. 439, Informed Consent* (p. 3). Retrieved 22 July 2019, from <https://www.acog.org/-/media/Committee-Opinions/Committee-on-Ethics/co439.pdf?dmc=1&ts=20151214T2054307809> ("Consenting freely is incompatible with [a patient] being coerced or unwillingly pressured by forces beyond [her] self."); American Medical Association. (2001). *AMA Code of Medical Ethics, Principles of Medical Ethics*. Retrieved 22 July 2019, from <https://www.ama-assn.org/sites/default/files/media-browser/principles-of-medical-ethics.pdf> ("A physician shall be dedicated to providing competent medical care, with compassion and respect for human dignity and rights."); American College of Physicians. *ACP Ethics Manual* (6th ed.). Retrieved 22 July 2019, from http://www.acponline.org/running_practice/ethics/manual/manual6th.htm ("The physician's primary commitment must always be to the patient's welfare and best interests, whether in preventing or treating illness or helping patients to cope with illness, disability, and death. The physician must respect the dignity of all persons and respect their uniqueness. The interests of the patient should always be promoted regardless of financial arrangements; the health care setting; or patient characteristics, such as decision-making capacity, behavior, or social status.") ("The physician must be professionally competent, act responsibly, . . . and treat the patient with compassion and respect . . .") ("Care and respect should guide the performance of the physical examination.")

erodes trust in the medical profession and in the health care system in ways that are harmful to all of us.

8. Language Access

The proposed rule would significantly weaken protections that provide access to interpretation and translation services for people with limited English proficiency (LEP).

More than 21 percent of the U.S. population (66 million people) speak a language other than English at home. Twenty five million individuals in the U.S. have LEP, meaning they speak little to no English.⁵³ For LEP individuals, language differences often compound and exacerbate existing barriers. LEP makes it difficult to navigate an already complicated health care system, especially when it comes to medical or insurance terminology. Language barriers are known to interfere with access to and the quality of care that people receive, for example the correct translation of medicines and medical conditions. Language barriers may also prevent people from accessing language services or may cause them to avoid health care altogether – resulting in delayed or misdiagnosis and treatment errors. For example, Spanish-speaking patients discharged from the emergency room are less likely than their English-speaking counterparts to understand their diagnosis, prescribed medications, special instructions and plans for follow-up care.⁵⁴

Research also shows significant disparities in patient safety between English-speaking and LEP hospital patients. LEP patients were more likely to experience medical errors due to communication problems than English-speaking patients, and more likely to suffer from physical harm when these errors occurred.⁵⁵ A 2010 report by the University of California, Berkeley School of Public Health and National Health Law Program found that of 1,373 malpractice claims, at least 35 were linked to inadequate language access.⁵⁶ Conversely, research has revealed that availability of language translation services is associated with fewer readmission rates and fewer malpractice claims. A 2017 study, for example, found that an academic hospital could save an estimated \$161,404 each month by avoiding 119 readmissions when patients had consistent access to language

⁵³ 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 (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).

⁵⁴ Crane JA. Patient comprehension of doctor-patient communication on discharge from the emergency department. *J Emerg Med.* 1997;15(1):1-7

⁵⁵ Divi C, Koss RG, Schmaltz SP, Loeb JM. Language proficiency and adverse events in US hospitals: A pilot study. *Int J Qual Health Care.* 2007;19(2):60-67.

⁵⁶ Quan, K., & Lynch, J. (2010). *The High Costs of Language Barriers in Medical Malpractice* (p.18). Retrieved 7 August 2019 from National Health Law Program website: http://www.pacificinterpreters.com/docs/resources/high-costs-of-language-barriers-in-malpractice_nhlp.pdf

interpretation.⁵⁷ These savings will be increasingly meaningful in value-based care arrangements.

Language barriers are also frequently compounded by discrimination based on national origin, immigration status, race, ethnicity, sexual orientation, and gender identity. Comprehensive language access is an important service that all health care providers should offer in order to achieve equitable, high-quality health care for all.

Section 1557 helps to ensure that people with LEP have access to culturally and linguistically appropriate care, including information about accessing services and health insurance. The proposed regulations would make the scope of Section 1557's language access provisions less clear, causing confusion and opening the door to illegal discrimination.

a) The proposed rule eliminates recommendations that entities develop language access plans.

Development of language access plans can 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 – however, if an entity has a language access plan, Section 1557 required that OCR must consider it when evaluating compliance. The proposed rule eliminates recommendations that entities develop language access plans, and removes the OCR consideration requirement.

Language proficiency should not determine whether people have access to care, or the quality of a person's care. By eliminating important 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.

We strongly recommend maintaining Section 1557's clear provisions supporting language access plans.

b) The proposed rule eliminates requirements for in-language taglines on significant communications.

The proposed rule eliminates requirements for covered entities to publish and disseminate disclosures for language assistance services for LEP individuals, including in-language taglines on significant communications.

Language assistance is necessary for LEP persons to access federally funded programs and activities in the healthcare system. Without these notices, members of the public will have limited means of knowing that language services and auxiliary aids and services are available or how to request them.

⁵⁷ Karliner, L. S., Pérez-Stable, E. J., & Gregorich, S. E. (2017). Convenient Access to Professional Interpreters in the Hospital Decreases Readmission Rates and Estimated Hospital Expenditures for Patients With Limited English Proficiency. *Medical care*, 55(3), 199–206. doi:10.1097/MLR.0000000000000643
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5309198/>

The inclusion of taglines is well-supported by long-standing federal and state regulations, guidance and practice, and is a cost-effective approach to ensuring that covered entities are not overly burdened while maintaining access for LEP individuals. Taglines are also important to ensure that individuals know their protections under the law. Combined with the elimination of the requirement to post notices of nondiscrimination (addressed later in these comments), eliminating requirements for taglines could leave many people without the knowledge of their own rights and further put legal services out of reach for those who are discriminated against.

Rather than eliminating taglines entirely, OCR could provide guidance on what constitutes a “significant document,” or how often an entity should consider providing taglines (e.g., to patients that receive frequent communication from their health care providers) to address concerns from providers about burden and cost while also upholding the civil rights of LEP persons.

We disagree that the language used in the nondiscrimination notice, taglines and language access plan provisions of the 2016 final rule were not justified by need, were overly burdensome and created inconsistent requirements. Finally, OCR’s regulatory impact analysis is insufficient and fails to identify and quantify costs to protected resulting from removal of the notice and tagline requirements.

- c) *The proposed rule also generally weakens existing language ensuring access for LEP individuals by:*
- Replacing Section 1557’s requirements that covered entities take reasonable steps to provide meaningful access to “each individual with LEP eligible to be served or likely to be encountered” with a more general reference to “LEP individuals;” and
 - Replacing the current test to determine when covered entities must provide language access services with one that removes the emphasis on the importance of the communication to the specific individual. Instead, the new language would allow HHS to balance a number of factors, including the number of eligible individuals, how often the individuals come into contact with the entity and the costs involved. Such language could encourage entities to avoid important protections and services for LEP people.

We strongly recommend maintaining Section 1557’s strong LEP provisions and language.

9. Notice Requirements

The proposed rule would remove the requirement to provide a notice of nondiscrimination, significantly limiting the ability of people to understand and enforce their rights.

We oppose the repeal of the requirement that covered entities provide a notice of nondiscrimination to inform the public of their legal rights. Without these notices, members of the public will have limited means of knowing what to do if they face discrimination, their right to file a complaint, and where to turn for help.

Research from the Kaiser Family Foundation points to significant concerns from underserved populations regarding discrimination in health care:

- 36% of Hispanics and 35% of African-Americans (compared to 15% of whites) felt they were treated unfairly in the health care system in the past based on their race and ethnicity.
- 65% of African-Americans and 58% of Hispanics (compared to 22% of whites) were afraid of being treated unfairly *in the future* based on their race/ethnicity.⁵⁸

The Administration's proposal to not provide this notice may leave people questioning how they will be treated when seeking health care, and subsequently avoiding or delaying treatment and care altogether. Indeed, 22% of African Americans and 18% of LGBTQ Americans say they have *avoided going to a doctor or seeking health care* out of concern that they would be discriminated against or treated poorly because of their race or LGBTQ identity.⁵⁹ This care-avoidant behavior not only has devastating consequences for health outcomes but ends up costing the system significantly in terms of delayed diagnosis and treatment onset and complications from aggravated medical conditions.

We strongly urge the Administration to maintain the requirement that covered entities provide a notice of nondiscrimination to inform the public of their legal rights.

10. Private Right of Action

The proposed rule eliminates essential mechanisms to ensure compliance with Section 1557, including a private right of action in federal courts.

Anti-discrimination protections should be vigorously enforced and must include mechanisms to ensure compliance. The 2016 final rule, like the statute itself, allows for a private right of action in federal court for individuals who have been harmed by violations of Section 1557. The proposed rule seeks to eliminate the right of private individuals and entities to file lawsuits in federal court to address violations. The proposed rule also attempts to eliminate the provision of the 2016 final rule that clarifies that money damages are available to compensate those injured by violations of Section 1557. In doing so, the proposed rule limits patients' rights to the legal system and threatens the integrity of Section 1557 by eliminating protections aimed at ensuring compliance.

We strongly recommend maintaining provisions to ensure compliance of Section 1557, including a private right of action.

11. Cost Analysis

⁵⁸ Kaiser Family Foundation. Race, Ethnicity, and Medical Care. A Survey of Public Perceptions and Experiences. <http://kff.org/disparities-policy/poll-finding/race-ethnicity-medical-care-a-survey-of/>. Accessed March 23, 2017.)

⁵⁹ NPR/Robert Wood Johnson Foundation/Harvard T.H. Chan School of Public Health, Discrimination in America: Experiences and Views of African Americans, January 26 – April 9, 2017. Q62a, Q88 Accessed online June 19, 2019 <https://www.npr.org/assets/img/2017/10/23/discriminationpoll-african-americans.pdf>

The proposed rule's cost analysis fails to account for the costs related to discrimination and denials of care.

The Department estimates that the proposed rule would result in approximately \$3.6 billion in cost savings. These savings would largely come from the elimination of taglines and notice standards – a direct assault on health and information access for people with LEP and others who are most marginalized, including LGBTQ people, people with disabilities and chronic conditions, people who have had abortions, people of color, and people are multiply marginalized. Furthermore, HHS has failed its legal obligation to fully and adequately account for the costs associated with this proposed rule. Under Executive Order 13563, an agency may only propose regulations where it has made a reasoned determination that the benefits justify the costs and where the regulations are tailored “to impose the least burden on society.” The proposed rule plainly fails on both counts. In particular, the proposed rule fails to account for the costs – to individuals, families, society and the economy – that result when people are discriminated against when attempting to access health care and/or are refused care altogether. Delays in or denials of care result in tangible increases to medical and health care system costs, and this regulation at best ignores that burden and at worst intends to maximize the harm to and burden on particular populations. If implemented, this proposed rule would actually increase public health costs, and health inequities - which already cost the U.S. economy \$309.3 billion a year⁶⁰ – would be exacerbated.

The administration should consider the significant cumulative burden of discrimination and related costs that this proposed rule would impose on patients and families.

Conclusion

Thank you for the opportunity to provide comment on the proposed rule. Section 1557 filled essential gaps in existing civil rights law to protect the most marginalized individuals and communities; we wholly reject the Administration's assertion that it is unnecessary and duplicative, and “not justified by need.” The effects of discrimination are profoundly harmful and costly, and require the thoughtful protections laid out in Section 1557. **We ask HHS to rescind the proposed rule in its entirety and, in doing so, ensure the protections afforded by Section 1557 remain in effect.**

⁶⁰ Thomas A. LaVeist, Darrel J. Gaskin., & Patrick Richard, The Economic Burden Of Health Inequalities in the United States, Joint Ctr. for Pol. and Econ. Stud. Retrieved 23 July 2019 from, <https://jointcenter.org/sites/default/files/Economic%20Burden%20of%20Health%20Inequalities%20Fact%20Sheet.pdf>