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August 13, 2019

Secretary Alex Azar
U.S. Department of Health and Human Services
Herbert H. Humphrey Building, Room 509F
200 Independence Ave SW
Washington, D.C. 20201

RE: Docket ID HHS-OCR-2019-0007, RIN 0945-AA11, Nondiscrimination in Health and Health Education Programs or Activities

Dear Secretary Azar,

On behalf of the National Alliance of State & Territorial AIDS Directors (NASTAD), which represents public health officials who administer state, local, and territorial HIV and hepatitis prevention and care programs, I appreciate the opportunity to provide comments to the proposed rule, rule entitled "Nondiscrimination in Health and Health Education Programs or Activities."

The Affordable Care Act (ACA) has expanded access to care for tens of thousands of people living with HIV who were previously uninsured or underinsured, in part, by prohibiting insurance practices that have limited access to care for people living with chronic and complex conditions or excluded them from coverage altogether. We are concerned that the proposed rule eliminates the very protections that have ensured access to lifesaving services for people living with and at high risk for HIV and hepatitis and will hamper our nation's efforts to end the HIV epidemic by 2030.

NASTAD strongly opposes the proposed elimination of critical protections guaranteed by Section 1557 of the ACA and the 2016 Nondiscrimination in Health Programs and Activities final rule ("2016 final rule"). We write to urge the Department of Health and Human Services (HHS) to rescind this notice of proposed rulemaking in its entirety.

No one should suffer from discrimination when they are seeking medical attention. Section 1557 is a civil rights law that protects people from being discriminated against and, like every other civil rights law, it should be upheld and enforced. The opportunity to access quality health care and live the healthiest possible life must be equally available to all and not selectively reserved for a few. Nobody should be turned away from care, with their health and lives put at risk, because of who they are.

That longstanding principle of health equity and fairness is why Section 1557 was signed into law. The proposed rule, however, will harm the communities Section 1557 was meant to protect, including people of color, women, people living with disabilities, people living with chronic conditions, seniors, people whose primary language is not English, immigrants, and LGBTQ individuals – all people who already experience significant barriers to accessing health care. Critically, Section 1557 specifically protects against intersectional discrimination, or discrimination based on multiple protected characteristics, by allowing people to file complaints of such discrimination in one place. We are deeply concerned that the proposed regulatory changes fail to reflect the broad protections provided by the law, and that the changes would only serve to obfuscate and weaken one of the nation's strongest nondiscrimination protections for vulnerable communities.

Federal protections that prohibit discrimination in health care based on disability, sexual orientation, and gender identity are critical in the fight to end HIV and hepatitis. Stigma continues to be a significant barrier to lifesaving HIV and hepatitis prevention and care, and federal laws and protections are necessary to combat stigma and the disparities in health care access and outcomes that stigma causes. The ACA's protections – including Essential Health Benefits and prohibitions on pre-existing condition exclusions, lifetime and annual benefit limits, and premium rating based on health status – have played a significant role in increasing coverage for individuals with chronic and complex health conditions by eliminating insurance practices that limited access to care or excluded these individuals from coverage altogether. Section 1557 combats subtler discriminatory practices that jeopardize LGBT health, limit access to care for people living with HIV, hepatitis, and other chronic health conditions, and create barriers to access to the most effective clinically recommended HIV and hepatitis treatments. This is particularly true for transgender individuals, for whom Section 1557 and the 2016 implementing regulation explicitly prohibited pervasive insurance discrimination, including arbitrary benefits exclusions.

While Section 1557 is still the law, this proposed rule attempts to change the administrative implementation in a way that is contrary to the plain language of the statute and amounts to an impermissible attempt to change legislation through administrative action. In order to reflect the ACA's clear intent and its overriding purpose of eliminating discrimination in health care, the proposed rule should not be finalized.

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

The Affordable Care Act was passed with the goal of ensuring that more people would have access to quality, affordable health insurance coverage and health care. To that end, Section 1557 prohibits discrimination on the basis of race, color, national origin, sex, age, or disability in certain federally funded health programs or activities. This means that health insurers, hospitals, clinics, and any other covered entities that receive federal funds cannot deny patients care on these grounds.

The proposed rule dramatically limits the scope of 1557 by applying inappropriate restrictions to the types of health programs and activities that must comply with Section 1557. The 2016 final rule made clear that Section 1557 applies to all health programs and activities that receive federal financial assistance from HHS. In keeping with the statutory language, 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, health-related insurance coverage, or other health-related coverage and assistance to individuals in obtaining these services or coverage. According to prior regulatory analysis, the 2016 final rule

covers about 900,000 physicians;[1] 133,343 facilities, including but limited to hospitals, nursing homes, rural health clinics, and federally qualified health centers; 445,657 clinical laboratories; 1,300 community health centers; 40 health-related schools and other health education entities; Medicaid and public health agencies in each state and the territories; and at least 180 insurers.[2] All of these entities are integral to the provision of essential health services that people living with HIV, hepatitis, and other chronic conditions need.

The proposed rule improperly attempts to narrow the application of Section 1557's protections to only the portions of certain health care programs or activities—specifically, those provided by entities that are not "principally engaged in the business of providing health care"—that receive federal financial assistance from HHS. This proposal therefore amounts to government subsidized discrimination, because entities that receive federal funds would still be permitted to discriminate on the basis of race, color, national origin, sex, age, or disability. Additionally, this proposal introduces a convoluted framework to determine whether an entity is considered a covered entity and thus subject to the Department's enforcement of these civil rights protections. These carve outs and distinctions are not only confusing to health programs and activities (who now must expend resources to clarify the required extent of their own compliance), but people living with HIV and other chronic illnesses as well as LGBT individuals will have difficulty determining when to expect compliance with nondiscrimination protections. People living with significant health needs require access to health programs and affordable health care plans that do not openly discriminate against members due to their race, color, national origin, sex (including gender identity, sexual orientation, and sex stereotypes; and pregnancy, childbirth, and related medical conditions), age, and disability. Additionally, the proposed changes would be unduly burdensome on consumers who would have to follow a vague, illogical scheme to determine when and where they can file complaints with the Office of Civil Rights ("OCR") about discrimination in the health setting.

By carving out entities who are not principally engaged in the business of providing health care services, HHS proposes an illogically narrow understanding of a "health program or activity", unnecessarily distinguishing "health insurance" from "health care." For people living with significant medical conditions, health insurance is often the only way to access the health care needed to manage chronic conditions. We are concerned that this change will dramatically limit the scope of nondiscrimination protections for health insurance products. The 2016 final rule, in keeping with the statutory language, prohibits insurers that receive federal financial assistance through participation in programs such as Marketplaces from discriminating in *any* of its lines of business. However, the proposed regulation would apply 1557 protections only to those products that receive federal financial assistance—such as Marketplace plans, Medicare Advantage Plans, Medicaid managed care plans, and some employee health benefit programs—and exempt all other lines of business, such as non-ACA products or third party administrator services, that are not federally funded or supported.[3] This has significant consequences for consumers who purchase short-term limited duration insurance

[1] Nondiscrimination in Health Programs and Activities, 81 Fed. Reg. 31,376, 31,446 (May 18, 2016) (concluding that "almost all practicing physicians in the United States are reached by Section 1557 because they accept some form of Federal remuneration or reimbursement apart from Medicare Part B").

[2] Nondiscrimination in Health Programs and Activities, 81 Fed. Reg. at 31,445. See, e.g., Katie Keith, *HHS Proposes to Strip Gender Identity, Language Access Protections From ACA Anti-Discrimination Rule*, HEALTH AFFAIRS BLOG (May 25, 2019), https://www.healthaffairs.org/do/10.1377/hblog20190525.831858/full/.

[3] MaryBeth Musumeci et al., *HHS's Proposed Changes to Non-discrimination Regulations under ACA Section 1557*, KAISER FAMILY FOUND. (Jul. 1, 2019), https://www.kff.org/disparities-policy/issue-brief/hhss-proposed-changes-to-non-discrimination-regulations-under-aca-section-1557/.

which, as NASTAD expressed in its comments to the proposed rule entitled *Short-Term, Limited Duration* insurance issued by the Departments of Health and Human Services, Labor, and Treasury last year, are already known to engage in discriminatory practices that significantly harm people living with HIV, hepatitis, and other chronic conditions. We are concerned that the proposal to explicitly exempt short-term, limited duration insurance from Section 1557's protections would embolden insurers to refuse to cover services that people living with chronic conditions need, or rescind coverage for higher-cost enrollees.

These changes unlawfully narrow the scope of Section 1557's application and are contrary to the statute, despite HHS' stated desire in revising its regulations to align more closely with the statutory text. Rather, the statute is clear that the law's provisions apply broadly to "any health program or activity, any part of which is receiving Federal financial assistance, including credits, subsidies, or contracts of insurance."[4] The proposal to limit Section 1557's application only to HHS-funded portions of health programs and activities is in direct opposition to Congress' intent that Section 1557 apply to "*any* health program or activity, *any* part of which is receiving Federal financial assistance" from HHS.

The 2016 final rule also made clear that Section 1557 applies to all health programs and activities administered by the Department, in addition to health programs and activities administered by entities established under Title I of the ACA. The proposed rule attempts to impermissibly narrow the scope of Section 1557 by excluding from its protections all programs and activities not administered under Title I of the ACA, including programs administered by the Department itself. This exempts from Section 1557 a number of programs that are essential in our efforts to end the HIV, hepatitis, and opioid epidemics and prevent new infections, including those administered by the Centers for Disease Control and Prevention, the Indian Health Service, and the Substance Abuse and Mental Health Services Administration.[5]

II. The Proposed Rule Impermissibly Attempts to Narrow the Scope of Sex Discrimination

Section 1557 is key to ensuring that everyone can access the care they need, free of discriminatory barriers, and enjoy the full benefits and protections of the ACA. It builds on longstanding federal civil rights laws – and is the first broad federal protection against discrimination based on sex in health care, designed to correct a pervasive history of sex discrimination. The 2016 final rule clarified that Section 1557 prohibits sex discrimination; protects transgender people based on gender identity; and protects LGBTQ people from discrimination on the basis of sex stereotypes.

Section 1557 has been essential to increase healthcare coverage and choices for millions of consumers who have historically been discriminated against in the healthcare system. Sex discrimination in health care has a disproportionate impact on LGBTQ people, women of color, and individuals living at the intersections of multiple identities – resulting in these individuals paying more for health care, receiving improper diagnoses at higher rates, being provided less effective treatments, and sometimes being denied care altogether. As the first broad prohibition against sex-based discrimination in health care, Section 1557 is crucial to ending gender-based discrimination in the health care industry. In addition to personal stories and lived experience, advocacy groups have submitted surveys, studies, and reports documenting discrimination in health care against these

[4] 42 U.S.C. § 18116(a).
[5] Keith, *supra* note 2.

communities and their families.[6] Although the uninsured rate among LGBTQ individuals has dropped dramatically since 2013, institutional discrimination on the basis of LGBTQ identity persists across the health care sector and acts as a deterrent to seeking care.[7] Repealing or weakening Section 1557's protections would increase costs for individuals who have serious medical needs, jeopardize the health and well-being of LGBTQ individuals, and set back the progress we have made in HIV and HCV prevention.

A. Sex Discrimination Based on Gender Identity and Sex Stereotyping

The 2016 final rule currently provides an accurate definition of sex and appropriately acknowledges that discrimination on the basis of sex includes discrimination on the basis of gender identity, including transgender and/or nonbinary status, and sex stereotyping. The 2016 final rule clarified that healthcare providers cannot refuse to treat someone because of their gender identity, and also prohibited discrimination based on association – for example, discrimination based on the fact that someone is in a relationship with a person of a certain gender identity.[8] The 2016 final rule also reiterated that sex stereotyping is a prohibited form of discrimination on the basis of sex, consistent with longstanding Supreme Court case law. The proposed rule illegally attempts to erase all reference to the ACA's protections against discrimination on the basis of gender identity and sex stereotyping. The proposal also exceeds the authority of OCR by impermissibly seeking to erase references to gender identity and sexual orientation across *all* HHS healthcare regulations, including longstanding regulations that are unrelated to Section 1557 and issued by other agencies within HHS.[9] If finalized, the proposal would only exacerbate existing disparities in transgender, nonbinary, and gender nonconforming individuals' ability to access HIV prevention and care services by providing legal cover to providers and issuers that refuse to provide or cover necessary medical care for all individuals on equal terms.

Although the proposed rule retains the general prohibition against sex-based discrimination in the provision or coverage of healthcare services, it would remove the current definition of discrimination "on the basis of sex," thus eliminating explicit protections against discrimination based on a person's gender identity and potentially allowing health programs and insurance plans to deny access to care or benefits to transgender individuals. This proposed change fails to consider the totality of case law regarding the interpretation of sex and fails to give proper weight to longstanding Supreme Court case law[10] and Circuit Court decisions[11] that have embraced a broad understanding of sex discrimination that includes discrimination on the basis of gender identity and sex stereotyping.

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[6] See, e.g., Public comments submitted in response to proposed rulemaking, Nondiscrimination in Health Programs and Activities, 80 Fed. Reg. 54,172 (proposed Sept. 8, 2015).

[7] *Discrimination in America: Experiences and Views of LGBTQ Americans*, NAT'L PUB. RADIO, ROBERT WOOD JOHNSON FOUND. AND HARVARD T.H. CHAN SCH. OF PUB. HEALTH (Nov. 2017), https://www.rwjf.org/content/dam/farm/reports/surveys_and_polls/2017/rwjf441734. Roughly 1 in 6 LGBTQ individuals surveyed reported being personally discriminated against when visiting a doctor or health clinic, and 18% said they have avoided going to a doctor or seeking health care out of fear that they would be discriminated against or treated poorly because of their LGBTQ identity. Among transgender respondents, 10% reported being personally discriminated against when they visited a doctor or health clinic, 22% said they avoid health care due to fear of discrimination, and 31% have no regular doctor or form of health care.

[8] Keith, *supra* note 2.

[9] *Id*.

[10] Price Waterhouse v. Hopkins, 490 U.S. 228 (1989) (finding that discrimination on the basis of sex, as prohibited in Title VII, included behavior based on expectations about how one should act or behave based on their sex).

[11] See, e.g., Zarda v. Altitude Express, Inc., 883 F.3d 100 (2nd Cir. 2018); Franchina v. Providence, No. 16-2401 (1st Cir. Jan. 25, 2018); Hively v. Ivy Tech, 853 F.3d 339 (7th Cir. 2017).

The proposal, if finalized, would eliminate the requirement that healthcare providers and other entities treat individuals consistent with their gender identity and allow such entities to deny access to health services and facilities based on gender identity.[12] In doing so, HHS would significantly set back our efforts to end the HIV epidemic by reducing transgender, nonbinary, and gender nonconforming individuals' access to HIV care and prevention services. Among the three million HIV testing events reported to CDC in 2017, the percentage of transgender people who received a new HIV diagnoses was three times the national average.[13] Despite the high prevalence of HIV among transgender individuals, nearly two-thirds of transgender individuals surveyed in 2014 and 2015 from 28 jurisdictions reported never testing for HIV.[14] This finding is consistent with other research showing that transgender, nonbinary, and gender nonconforming people often avoid care out of fear of discrimination due to experiencing high rates of discrimination and harassment in healthcare settings. According to the 2015 U.S. Transgender Survey, 33 percent had at least one negative experience in a health care setting relating to their gender identity in the previous year.[15] According to a 2018 study from the Center for American Progress, 23 percent had a provider intentionally misgender or use the wrong name for them, 21 percent had a provider use harsh or abusive language when treating them,[16] and 29 percent experienced unwanted physical contact, such as fondling, sexual assault, or rape, from a provider.[17] The 2015 U.S. Transgender Survey also found that 23 percent of transgender, nonbinary, and gender nonconforming people did not seek health care when they needed it due to fear of being disrespected or mistreated on the basis of their gender identity.[18] Research shows that such negative experiences with providers leads to avoidance of health care settings altogether, which leads to decreased engagement with and retention in HIV care.[19] Rather than exacerbating these disparities by giving medical providers legal cover when they discriminate against individuals on the basis of gender identity, we urge HHS to continue monitoring compliance with Section 1557 and working to strengthen these protections.

The 2016 final rule further clarified that insurance companies cannot categorically exclude or deny coverage for gender-affirming care. The proposed rule illegally attempts to open the door to insurance companies categorically excluding coverage of gender-affirming care from their plans, denying individuals coverage of procedures used for gender affirmation, imposing higher costs for services related to gender-affirming care, or imposing higher costs for services ordinarily available to individuals of one sex or gender based on the fact that the individual's recorded sex in medical or insurance records differs from the one to which such health services are ordinarily provided. Insurance companies have historically used such practices to deny transgender people coverage for

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[12] Keith, *supra* note 2.
[13] *HIV and Transgender People*, CTRS. FOR DISEASE CONTROL & PREVENTION, https://www.cdc.gov/hiv/group/gender/transgender/index.html (last visited July 31, 2019).
[14] *Id*.
[15] S.E. James et al., *Report Of The 2015 U.S. Transgender Survey*, NAT'L CTR. FOR TRANSGENDER EQUALITY 96-97 (2016), https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf. Rates were higher for Native respondents (50 percent), Middle Eastern respondents (40 percent), multiracial respondents (38 percent), and respondents with disabilities (42 percent).
[16] Shabab Ahmed Mirza and Caitlin Rooney, *Discrimination Prevents LGBTQ People from Accessing Health Care*, CTR. FOR AM. PROGRESS (Jan. 18, 2018), https://www.americanprogress.org/issues/lgbt/news/2018/01/18/445130/discrimination-prevents-lgbtq-people-accessing-health-care/.
[17] *Id*.
[18] James et al., *supra* note 15.
[19] Jae M. Sevelius, PhD et al., *Barriers and Facilitators to Engagement and Retention in Care Among Transgender Women Living with Human Immunodeficiency Virus*, 47 ANNALS BEHAV. MED. 5 (2014).

medically necessary care, including hormone therapy, mental health counseling, and surgeries. As a result, gender-affirming care was financially out of reach for most transgender individuals, since transgender individuals are disproportionately living with lower incomes and therefore cannot afford the care they need without comprehensive, affordable coverage. However, as a result of Section 1557 and the 2016 final rule, many insurers removed categorical coverage exclusions harming transgender people and began to cover gender-affirming services,[20] increasing access to care. HHS asserts that consumers could not have developed a reliance interest on these protections because these provisions of the 2016 final rule did not go into effect until January 2017 and were enjoined by a federal court on December 31, 2016.[21] This assertion is unfounded. Insurers filed their 2017 products well in advance of the court's injunction, and analyses of individual market plans for 2017, 2018, and 2019 shows that the vast majority—at least 90%—of individual market insurers in the federal Marketplace complied with Section 1557 and did not include transgender-specific exclusions in their plans, likely as a result of federal protections.[22] Research shows that access to gender affirming health care, including access to transition-related healthcare such as hormones and surgery, is associated with higher rates of engagement with and retention in HIV care.[23] Retaining Section 1557's protections against discrimination on the basis of gender identity is therefore crucial to our country's efforts to eliminate HIV.

By permitting discrimination on the basis of sex stereotyping, the proposal would have a disproportionate impact on LGBTQ individuals' ability to access essential medical care, including HIV care. LGBTQ people already experience significant discrimination in health care. For example, seven percent had a provider refuse to recognize their family, including a child or a same-sex spouse/partner, and nine percent had a provider use harsh or abusive language when treating them.[24] Further, seven percent experienced unwanted physical contact from provider, including fondling, sexual assault, or rape.[25] However, discrimination based on sex stereotypes can affect *anyone* who does not conform to traditional societal expectations of their sex, regardless of their actual gender identity, sexual orientation, or sex. For example, the proposed rule illegally purports to allow a health care provider to refuse to provide maternity care to an unmarried woman—including HIV care necessary to prevent transmission to her baby and ensure optimal health outcomes for the mother—or to refuse to provide HIV care to a man whom the provider believes is "too feminine," regardless of the patient's gender identity. As such, Section 1557's protections against discrimination on the basis of sex do not only benefit a certain subset of people, but rather address the broad impact that discrimination can have on all individuals, families, and communities. The proposed rule impermissibly attempts to open the door to further discrimination against *all* individuals that do not conform to sex-based stereotypes.

B. Sex Discrimination Based on Pregnancy

Sex discrimination takes many forms and has the potential to occur at every step in the health care system—from obtaining insurance coverage, to receiving proper diagnosis and treatment, to

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[20] *Summary of Findings: 2019 Marketplace Plan Compliance with Section 1557*, OUT2ENROLL, https://out2enroll.org/out2enroll/wp-content/uploads/2018/11/Report-on-Trans-Exclusions-in-2019-Marketplace-Plans.pdf (last visited July 17, 2019).
[21] Keith, *supra* note 2.
[22] *Id*.
[23] Sevelius et al., *supra* note 19, at 5.
[24] Mirza and Rooney, *supra* note 16.
[25] *Id*.

harassment by a provider. Such discrimination has serious adverse impacts on the lives of women, especially pregnant women and pregnant or non-pregnant women living with HIV, hepatitis, and other chronic conditions, causing them to pay more for health care and to risk receiving improper diagnoses and less effective treatments. The effects of sex discrimination for women of color may be compounded by other forms of discrimination they face, including racial discrimination and discrimination based on language proficiency.

The 2016 final rule made clear that sex discrimination under Section 1557 includes discrimination on the basis of pregnancy, false pregnancy, termination of pregnancy or recovery therefrom, childbirth, or related conditions. The proposed rule attempts to roll back these protections, creating a system where pregnant women living with HIV, hepatitis, and other chronic conditions may not be able to access the care they need. Although HHS acknowledges in the preamble to this proposed rule that the prohibition against sex discrimination includes termination of pregnancy, it refuses to state whether the Department would enforce those protections and proposes to delete the 2016 final rule's clarification that the ban on sex discrimination includes all pregnancy-related care. In doing so, the Department illegally attempts to eliminate the express protections that apply to someone who has had an abortion or has experienced a miscarriage or ectopic pregnancy and needs care for those or other conditions. While the scope of protection under Section 1557 is clear, without unambiguous implementing regulations and enforcement, illegal discrimination is likely to flourish.

Pregnant women living with HIV need a number of medical services to ensure optimal health outcomes for themselves and their babies. The CDC's *Preconception Care Work Group's Recommendations to Improve Preconception Health and Health Care* include a number of recommendations for providers treating pregnant women living with HIV, including but not limited to counseling women about risk factors for perinatal transmission of HIV and strategies to reduce those risks, making referrals to experts in HIV and women's health, evaluating treatment options for potential teratogenicity or other adverse outcomes for mother and baby, optimizing viral suppression while minimizing adverse effects of antiretroviral therapies, and postpartum care for both mother and child.[26] The CDC's recommendations also address providing care to women living with HIV who may experience interactions between hormonal contraceptives and antiretroviral therapy, as well as preconception care and counseling for women living with HIV who are considering pregnancy. By removing discrimination on the basis of pregnancy from the definition of discrimination on the basis of sex under Section 1557, the proposal would allow providers to refuse to provide these and other critical medical services to pregnant women living with HIV and women of child-bearing age living with HIV. Absent access to non-discriminatory health care, women living with HIV may not know they are pregnant, how to prevent or safely plan pregnancy, or what they can do to prevent transmission to their babies.

Retaining Section 1557's protections against discrimination on the basis of pregnancy is also critical for HIV prevention. Many women in the United States do not get tested for HIV during pregnancy, and women living with HIV who do not get tested often transmit HIV to their infants. A pregnant women living with HIV who is not in care has a one in four chance of transmitting HIV to her child; however, 99 percent of pregnant women living with HIV who receive appropriate medical treatment

[26] Kay Johnson, MPH et al., *Recommendations to Improve Preconception Health and Health Care: A Report of the CDC/ATSDR Preconception Care Work Group and the Select Panel on Preconception Care*, CTRS. FOR DISEASE CONTROL & PREVENTION (Apr. 21, 2006), https://www.cdc.gov/mmwr/preview/mmwrhtml/rr5506a1.htm.

will not transmit HIV to their babies.[27] The earlier HIV is diagnosed and treated, the more effective HIV treatment will be at preventing transmission and improving the health outcomes of both mother and child.[28] The proposed rule would also jeopardize access to pre-exposure prophylaxis (PrEP) for HIV-negative women who have a partner living with HIV, limiting women's ability to protect themselves and their babies during pregnancy and while breastfeeding. Rather than allowing providers to discriminate against pregnant women living with HIV and refuse to provide them with necessary care, HHS should promote policies that expand access to HIV testing and care for pregnant women and women of child-bearing age.

For women who already experience discrimination in health care on the basis of their race, color, or national origin, the consequences of HHS' proposal would be especially severe. For example:

- The proposed rule could place Black women at greater risk of pregnancy-related complications. Black women already experience significant disparities in the care they receive during pregnancy and childbirth, and are three-to-four times more likely to die from pregnancy related complications than white women.[29] Pregnancy-related complications are among the ten leading causes of death for Black women aged 15-34 years.[30] Additionally, Black women accounted for 64 percent of diagnosed perinatal HIV transmissions in 2017.[31] Given the disproportionate negative impact of racism on the quality of care women receive during pregnancy and childbirth, HHS' proposal to essentially legitimize discrimination on the basis of pregnancy would disproportionately lead to adverse health outcomes for Black women, including and especially women living with or at risk of HIV, hepatitis, and other chronic conditions, and their children.
- The proposed rule could also be used to deny Asian American and Pacific Islander ("AAPI") communities access to crucial services such as emergency contraceptives and prenatal care. Language and cultural barriers already prevent AAPI women from accessing culturally and linguistically appropriate care. AAPI women use less effective contraceptive methods at much higher rates compared to women of other races and ethnicities, placing AAPI women at greater risk of unintended pregnancy.[32] AAPI mothers are less likely than others to receive early and adequate prenatal care, especially Laotian and Cambodian women.[33] One study found that AAPI women are twice as likely to die from pregnancy-related causes, including embolism and pregnancy-related hypertension.[34] AAPIs are also the fastest growing

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[27] *HIV and Other Important Pregnancy Tests*, AM. COLLEGE OF OBSTETRICIANS & GYNECOLOGISTS (2011), https://www.acog.org/-/media/Departments/HIV/HIV--OtherPregnTsts-tear-pad1.pdf.

[28] *HIV and Pregnant Women, Infants, and Children*, CTRS. FOR DISEASE CONTROL & PREVENTION, https://www.cdc.gov/hiv/group/gender/pregnantwomen/index.html (last updated June 12, 2019).

[29] See, e.g., Miquel Davies, *Racism in Health Care – For Black Women Who Become Pregnant, It's A Matter of Life and Death*, NAT'L WOMEN'S LAW CTR. (Apr. 13, 2018), https://nwlc.org/blog/racism-in-health-care-for-black-women-who-become-pregnant-its-a-matter-of-life-and-death/ (discussing the negative impact of racism in health care on the quality of care Black women receive during pregnancy and childbirth, including disproportionate maternal death rates among Black women).

[30] Cynthia Prather et al., *The Impact of Racism on the Sexual and Reproductive Health of African American Women*, 25(7) J. WOMEN'S HEALTH 664, 664-671 (2016).

[31] *HIV and Pregnant Women, Infants, and Children*, supra note 28.

[32] Jo Jones, et al., U.S. Dep't of Health & Human Servs., *Current Contraceptive Use in the United States, 2006-2010, and Changes in Patterns of Use Since 1995*, 60 NAT'L HEALTH STATISTICS REPORT 1, 5 (Oct. 18, 2012), https://www.cdc.gov/nchs/data/nhsr/nhsr060.pdf.

[33] LORA JO FOO, ASIAN AMERICAN WOMEN: ISSUES, CONCERNS, AND RESPONSIVE HUMAN AND CIVIL RIGHTS ADVOCACY 106 (Ford Foundation 2002).

[34] Marcus T. Smith, *Fact Sheet: The State of Asian American Women in the United States*, CTR. FOR AM. PROGRESS (Nov. 7, 2013), https://www.americanprogress.org/issues/race/reports/2013/11/07/79182/fact-sheet-the-state-of-asian-american-women-in-the-united-states/.

population in the United States with documented increases in HIV rates[35] and have lower diagnosis rates compared with other racial and ethnic groups;[36] HHS' proposal would exacerbate these existing disparities and lead to worse health outcomes for AAPI pregnant women living with or at risk of HIV, hepatitis, and other chronic conditions.

- Additionally, HHS' proposal would disproportionately impact Latina and Latinx populations, for whom lack of access to comprehensive, affordable insurance coverage already means sporadic, if not non-existent, access to desperately needed treatment and services. Due to this and other factors, Latinas experience disproportionately high rates of unintended pregnancy, as well as HIV and other chronic conditions. Hispanic women are four times as likely to be diagnosed with HIV compared to non-Hispanic White women, and are four times as likely to have AIDS.[37] Hispanic women are also four times as likely as non-Hispanic White men to die from HIV infection.[38] By impermissibly allowing healthcare providers to discriminate against individuals seeking care on the basis of pregnancy, HHS' proposal would exacerbate these existing disparities and lead to worse health outcomes for Latina pregnant women living with or at risk of HIV, hepatitis, and other chronic conditions.

C. Religious Exemptions

We also oppose any attempts to add new religious or moral exemptions to existing federal non-discrimination protections. The proposed rule attempts to impermissibly apply Title IX's religious exemption to Section 1557's prohibition on sex discrimination, which would affect overall access to care for women and others because a religious provider could say they do not have to comply with sex discrimination protections.[39] The Department's attempt to incorporate a religious exemption violates the plain language of the statute and is contrary to the express purpose of Section 1557. If implemented, this could allow for religiously-affiliated hospitals and other health care entities to discriminate against patients based on sex, disproportionately harming LGBTQ people, people seeking reproductive health services, people who use drugs, people living with chronic conditions such as HIV and hepatitis, and those living at the intersection of protected identities.

Allowing a religious exemption to Section 1557's protection against sex discrimination could have far reaching consequences. Incorporating Title IX's religious exemption could create new instances in which healthcare providers and insurance companies can allow their beliefs to determine patient care, opening the door to illegal discrimination. This could impact a broad range of health care services, including birth control, sterilization, certain fertility treatments, abortion, gender-affirming care, end-of-life care, and care for HIV, hepatitis, and other chronic conditions. Moreover, there is already a proliferation in the types of entities that are now emboldened to use religious beliefs to discriminate against patients, as well as in the number of religiously-affiliated entities that provide

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[35] Soma Sen at al., *HIV Knowledge, Risk Behavior, Stigma, and Their Impact on HIV Testing among Asian American and Pacific Islanders: A Review of Literature*, 32 SOC. WORK PUB. HEALTH 11 (2016).

[36] *HIV and Asians*, CTRS. FOR DISEASE CONTROL & PREVENTION, https://www.cdc.gov/hiv/group/racialethnic/asians/index.html (last visited July 31, 2019).

[37] *HIV/AIDS and Hispanic Americans*, OFFICE OF MINORITY HEALTH, U.S. DEP'T OF HEALTH & HUMAN SERVS., https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=4&lvlid=66 (last visited July 31, 2019).

[38] *Id.*

[39] Candace Gibson & Wayne Turner, *Questions and Answers On the Proposed Rollback of Nondiscrimination Protections Under the ACA's Section 1557*, NAT'L HEALTH LAW PROGRAM 6-7 (June 14, 2019), https://9kqpw4dcaw91s37kozm5jx17-wpengine.netdna-ssl.com/wp-content/uploads/2019/06/1557-Reg-Revision-QA-updated-6.14.2019.pdf.

health care and related services that refuse to provide care based on religious beliefs.[40] The proposed rule could encourage these entities to further engage in illegal discrimination.

Section 1557 already includes a range of religious exemptions excepting covered entities from requirements that conflict with their religious or moral beliefs in a wide variety of circumstances. The 2016 final rule explicitly did *not* override other federal statutory protections for religious freedom and conscience, providing health care providers and other covered entities with the ability to claim religious exemptions under The Religious Freedom Restoration Act and other laws.[41] Adding additional exemptions from requirements related to discrimination on the basis of sex or any other grounds is unnecessary and would harm the very populations that Section 1557 is designed to protect. More expansive religious exemptions would permit providers to refuse to provide medically necessary treatment to individuals simply on the basis of religion, gender, drug use, HIV status, sexual orientation, or gender identity. For example, a pharmacist could illegally refuse to fill prescriptions for HIV medications for patients who are LGBTQ or unmarried. This could cause delays in medically necessary treatment, leading to adverse individual and public health consequences. Expanding religious exemptions could be especially harmful in situations where individuals have limited choice of providers, such as in rural areas, or in emergency situations where there is limited opportunity to shop for providers.[42] There are already numerous barriers to accessing HIV prevention and care services in many rural communities, such as limited resources, lack of awareness about HIV prevalence, and lack of services and providers;[43] HHS should advance policies that reduce those barriers rather than compound them. The proposal to allow for additional religious exemptions would exacerbate the negative consequences of other portions of HHS' proposal discussed throughout this comment and will disproportionately impact communities of color and other underserved populations—particularly those in need of HIV prevention and care services.

III. The Proposed Rule Impermissibly Would Eliminate Language Access Protections

Discrimination on the basis of national origin includes, but is not limited to, discrimination on the basis of language and language proficiency. Language assistance is necessary for limited English proficient (LEP) persons to access federally funded programs and activities in the health care system. The 2016 final rule therefore included protections for LEP individuals, which the Department now proposes to eliminate. The proposed repeal of notices, taglines, and language access plans threatens the civil rights of LEP persons. The impact of this proposal is further compounded by other proposed changes, including narrowing the scope of Section 1557's applicability to healthcare entities and erasing references to the ACA's protections against discrimination on the basis of sex.

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[40] See, e.g., Lois Uttley et al., *Miscarriage of Medicine: the Growth of Catholic Hospitals and the Threat to Reproductive Health Care*, AM. CIVIL LIBERTIES UNION & MERGER WATCH (2013), https://www.aclu.org/files/assets/growth-of-catholic-hospitals-2013.pdf.

[41] Keith, *supra* note 2.

[42] Mirza and Rooney, *supra* note 16. For example, a 2018 study found that 18 percent of LGBTQ people said that, if they were turned away from receiving care, it would be difficult or impossible to find the same type of service at a different hospital, while 17 percent said it would be difficult or impossible to find the same type of service at another clinic. These rates were higher for LGBTQ people living outside of metropolitan areas—41 percent said it would be difficult or impossible to find the same type of service at a different hospital and 31 percent said it would be difficult or impossible to find the same type of service at a different clinic.

[43] *Barriers to HIV/AIDS Care in Rural Communities*, RURAL HEALTH INFORMATION HUB, https://www.ruralhealthinfo.org/toolkits/hiv-aids/1/rural-barriers (last visited July 31, 2019).

Over 21 percent of the U.S. population, or 66 million people, speak a language other than English at home, with 25 million of them speaking English less than "very well" and thus considered LEP.[44] Additionally, 19 million LEP adults are uninsured.[45] For LEP individuals, language differences often compound existing barriers to accessing and receiving appropriate care. Limited English proficiency often makes it difficult to navigate an already complicated healthcare system, especially when it comes to medical or insurance terminology. Moreover, these barriers are often compounded by discrimination based on national origin, immigration status, race, ethnicity, sexual orientation, and gender/gender identity.

We strongly disagree that the 2016 final rule's requirement to include nondiscrimination language in notices, taglines, and language access plans 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. These notices are not redundant because HHS created the option of using one consolidated civil rights notice to minimize burden on covered entities. Without the notice, members of the public will have limited means of knowing that language services and auxiliary aids and services are available and how to request them, what to do if they face discrimination, and their right to file a complaint. Taglines are well supported by existing federal and state regulations, guidance, and practice, and are a cost-effective approach to ensure that covered entities are not overly burdened. In the absence of translated documents, taglines are necessary to ensure that individuals are aware of their protections under the law.[46]

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

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[44] *2017 American Community Survey 1-Year Estimates: Table S1603 Characteristics of People by Language Spoken at Home*, U.S. CENSUS BUREAU, https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_17_1YR_S1603&prodType=table (last visited Jul. 31, 2019); *2017 American Community Survey 1-Year Estimates: Table S1601 Language Spoken at Home*, U.S. CENSUS BUREAU, https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_17_1YR_S1601&prodType=table (last visited Jul. 17, 2019).

[45] Asian & Pacific Islander American Health Forum Analysis of 2017 American Community Survey Public Use Microdata Sample Files.

[46] See, e.g., Public comments submitted in response to proposed rulemaking, Nondiscrimination in Health Programs and Activities, 80 Fed. Reg. 54,172 (proposed Sept. 8, 2015).

IV. The Proposed Rule Would Eliminate Prohibitions on Discrimination in Insurance Plan Benefit Design and Marketing

Over 133 million people in the United States live with at least one chronic condition,[47] and over 61 million people are living with a disability.[48] Approximately 1.1 million people are living with HIV,[49] and anywhere from 2.5 to 4.7 million people are estimated to be living with hepatitis C.[50] Additionally, since 2012, there have been more deaths due to hepatitis C than all 60 of the other reportable diseases combined.[51] Section 1557's protections ensuring affordable, comprehensive access to coverage and health services to all on equal terms, regardless of health status, are therefore crucial to ensuring the health and well-being of millions of people.

Before the ACA, health insurers routinely discriminated against people living with HIV and other chronic conditions by charging them exorbitant premiums, excluding coverage for their conditions, or refusing to provide health coverage at all. The ACA addressed these issues by prohibiting insurers from charging higher premiums or denying coverage for people with pre-existing conditions. Section 1557 also prohibits covered entities from using discriminatory marketing practices, such as those "designed to encourage or discourage particular individuals from enrolling in certain health plans."[52] Despite these protections, insurers still sought ways to discourage people with significant health conditions from enrolling in their plans. One such tactic is adverse tiering—placing treatments for certain chronic conditions, including HIV and hepatitis, on high cost-sharing tiers.[53] Adverse tiering puts these medications financially out of reach for most people, despite the fact that they have insurance coverage. Although people living with other chronic conditions could no longer be denied coverage or charged higher premiums following the passage of the ACA, they were often still unable to afford the health care they needed.

The National Health Law Program and The AIDS Institute filed a complaint with HHS OCR charging that four issuers in Florida discriminated against persons living with HIV by placing all HIV treatments, including generics, on the highest cost-sharing tiers.[54] Researchers at the Harvard School of Public Health found that the practice of placing HIV drugs in the highest cost sharing tiers was widespread.[55] The Pharmaceutical Research and Manufacturers Association (PhRMA) conducted an analysis of 123

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[47] *The Growing Crisis of Chronic Disease in the United States*, P'SHIP TO FIGHT CHRONIC DISEASE, https://www.fightchronicdisease.org/sites/default/files/docs/GrowingCrisisofChronicDiseaseintheUSfactsheet_81009.pdf (last visited Jul. 17, 2019).

[48] *1 in 4 US Adults Live with a Disability*, Press Release, CTRS. FOR DISEASE CONTROL & PREVENTION (Aug. 16, 2018), https://www.cdc.gov/media/releases/2018/p0816-disability.html.

[49] *U.S. Statistics: Fast Facts*, HIV.GOV, http://www.hiv.gov/hiv-basics/overview/data-and-trends/statistics (last visited Aug. 2, 2019).

[50] *Viral Hepatitis in the United States: Data and Trends*, DEP'T OF HEALTH & HUMAN SERVS., http://www. https://www.hhs.gov/hepatitis/learn-about-viral-hepatitis/data-and-trends/index.html (last visited Aug. 2, 2019).

[51] *Id*.

[52] Musumeci et al., *supra* note 3.

[53] National Health Law Program & The AIDS Institute, Re: Discriminatory Pharmacy Benefits Design in Select Qualified Health Plans Offered in Florida, Administrative Complaint filed with the HHS Office for Civil Rights (May 28, 2014), https://healthlaw.org/resource/nhelp-and-the-aids-institute-complaint-to-hhs-re-hiv-aids-discrimination-by-fl/. See also, *Coverage of Hepatitis B & C Drugs Difficult to Access in Florida's Health Plans*, Press Release, THE AIDS INST. (Oct. 5, 2015), http://www.theaidsinstitute.org/sites/default/files/attachments/10-05-15%20TAI%20Release%20-%20FL%20QHPs%20(1).pdf (describing discriminatory insurer practices placing hepatitis B, hepatitis C, and HIV treatments on high cost-sharing tiers, with coinsurance as high as 30 to 50 percent).

[54] Gibson & Turner, *supra* note 39, at 6-7.

[55] *Id*.

Marketplace plans and similarly concluded that insurance companies routinely applied adverse tiering to treatments for other chronic conditions, including cancer and multiple sclerosis.[56] PhRMA concluded that there was a "lack of adequate formulary scrutiny on the part of state and federal regulators" because "[r]equiring high cost-sharing for all medicines in a class is exactly the type of practice the ACA was designed to prevent."[57]

HHS agreed with PhRMA's conclusions, and therefore expressly prohibited insurers from designing benefits that discourage enrollment by persons with significant health needs in the 2016 final rule. This includes discriminatory health insurance plan designs that impose burdensome prior authorization requirements on HIV and HCV medications, or use adverse tiering to place these medications on high cost-sharing tiers.[58] The 2016 final rule specifically cited to the practice of placing all drugs used to treat a certain condition, such as HIV, as an example of discriminatory plan design prohibited under Section 1557.[59] The proposed rule would remove the current prohibition on discriminatory plan design, which essentially functions as a pre-existing condition exclusion because people with pre-existing conditions would be unable to access the care they need.

Despite these protections, we continue to see discriminatory benefit designs that bar people living with complex and chronic conditions from access to care. Instead of weakening or eliminating this important protection, we urge HHS to better enforce the provisions articulated in Section 1557 and the 2016 final rule, including assessing the presence of the specific examples of discriminatory plan designs described above. Additionally, limitations to curative HCV treatment that are not based on clinical recommendations, including fibrosis score and sobriety/abstinence requirements, should be included as examples of discriminatory plan designs based on disability.

V. Conclusion

Although Section 1557 is still law, the proposed rule would almost entirely replace the 2016 final rule that made clear what forms of discrimination are prohibited by Section 1557. The proposed rule is not justified and seeks to impermissibly depart from the statutory text of Section 1557 and the 2016 final rule, which was finalized after considerable public comment, including a request for information and one notice of proposed rulemaking. By replacing most of the 2016 final rule with unclear regulations, the proposed rule, if finalized, would create confusion and could open the door to illegal discrimination.

In direct opposition to the text of Section 1557, the proposed rule improperly seeks to exempt many health insurance plans from the anti-discrimination provisions, as well as any health program or activity run by HHS that was not created by Title I of the ACA. It eliminates regulations pertaining to the fundamental requirement that all beneficiaries, enrollees, applicants, and members of the public receive notice of their rights under Section 1557 and removes important regulations that protect individuals with limited English proficiency. It improperly tries to incorporate Title IX's religious exemption, which could permit healthcare entities controlled by a religious organization to discriminate if the entity claims complying with sex discrimination and other protections conflicts with its religious beliefs. The rule attempts to overrule decades of federal court precedent by trying

[56] *Id*.
[57] *Id*.
[58] See, e.g., Musumeci et al., *supra* note 3.
[59] Gibson & Turner, *supra* note 39, at 6-7.

to eliminate protections against discrimination based on gender identity, and completely disregards Supreme Court precedent on discrimination based on sex stereotyping. The proposed rule also opens the door for insurance companies to use tactics such as adverse tiering to discourage enrollment by people living with chronic conditions, and amounts to a pre-existing exclusion because people living with chronic conditions would be unable to access the care and treatment they need.

The NPRM's proposed changes pose significant risks to those the law is intended to protect, including LGBTQ people, people who need reproductive health care, including abortion, women of color, people living with disabilities and/or chronic conditions, and people whose primary language is not English–all people who already experience significant barriers to accessing health care. The proposed changes could create additional barriers and potentially lead to worse health outcomes, disproportionately impacting those living at the intersections of these identities. For example, a woman who is transgender and living with HIV could experience compounded discrimination based on her being a woman, being transgender, and living with HIV.

Without strong, clear rules prohibiting discrimination, there will be unequal access to health coverage and health care. Rather than being distributed equally, the burdens of a lack of healthcare coverage and healthcare denials fall disproportionately on communities of color and other underserved populations, which are more likely to experience higher rates of unemployment, to have jobs that do not provide health insurance, and to have lower incomes that put higher insurance premiums out of their financial reach.

We are opposed to reopening, repealing, or weakening the 2016 final rule implementing Section 1557 and its crucial protections against discrimination in health care. We urge HHS to instead uphold federal law and the intent of Section 1557 by preserving and strengthening these important protections.

If you have questions or need additional information, please contact me at 202-434-8000, or tmoore@nastad.org.

Sincerely,

Terrance E. Moore

Terrance E. Moore
Acting Executive Director