August 13, 2019

Secretary Alex Azar  
Department of Health and Human Services  
Hubert H. Humphrey Building, Room 509F,  
200 Independence Avenue SW,  
Washington, DC 20201

Re: Section 1557 NPRM, RIN 0945-AA11, “Nondiscrimination in Health and Health Education Programs or Activities”

Community Catalyst submits these comments in response to the Department of Health and Human Services’ (“HHS”, “Department”) and the Center for Medicare and Medicaid Services (“CMS”) Notice of Proposed Rulemaking (“proposed rule,” “NPRM”) entitled “Nondiscrimination in Health and Health Education Programs or Activities.”

Community Catalyst is a national consumer health advocacy organization working at the local, state and federal levels. Our mission is to organize and sustain a powerful consumer voice to ensure that all individuals and communities can influence the local, state and national decisions that affect their health. We work with state and local consumer health advocates in more than 40 states to improve coverage and access to quality, affordable health care. One key focus of our work has been fighting discrimination in health care because it leads to disturbing and harmful disparities in health coverage, access and outcomes.

We are deeply concerned by the proposed rule, which seeks to undermine long-needed health care nondiscrimination protections established by the Affordable Care Act. This rule would especially harm those individuals who are already disproportionately affected by health disparities, such as transgender and gender nonconforming people, the entire LGBTQ community, people needing abortion services and people whose first language is not English. The rule could send the wrong message to health providers, suggesting incorrectly that it is legally permissible to discriminate against transgender patients. It could embolden insurance companies to return to harmful practices of denying transgender people coverage for health care services that they cover for non-transgender people. The rule would also make it harder for other people experiencing discrimination in health care to know and exercise their rights, including people with Limited English Proficiency (LEP) and people suffering from chronic health conditions, like HIV.

Both our employees and the people we advocate for across the United States would be harmed by this attempt to sanction discrimination in health care. Community Catalyst
urges the Department of Health and Human Services (HHS) to withdraw the entire proposed rule.

I. The Proposed Rule Impermissibly Attempts to Narrow the Definition of Sex Discrimination

As the first broad prohibition against sex-based discrimination in health care, Section 1557 is crucial to ending gender-based discrimination in health care access and coverage across the United States. Sex discrimination in health care especially affects women of color, low-income women, LGBTQ people (especially transgender and gender non-conforming people) and individuals living at the intersections of multiple identities. The result can be that these individuals must pay more for health care, receive improper diagnoses at higher rates, are provided less effective treatments and sometimes are denied care altogether. In addition to personal stories highlighting such problems, there have been countless surveys, studies, and reports documenting discrimination in health care against these communities and their families.

The 2016 final rule implementing Section 1557 had clarified that health care providers cannot refuse to treat someone because of their gender identity. The proposed rule illegally purports to allow a health care provider to refuse to treat someone because of their gender identity. For example, a doctor could refuse to treat a transgender person for a cold or a broken bone, simply because of their gender identity.

The 2016 final rule also clarified that insurance companies cannot categorically exclude or deny coverage for gender-affirming care. The proposed rule illegally attempts to again open the door to insurance companies categorically excluding coverage of gender-affirming care from their plans or denying individuals coverage of procedures used for gender affirmation. Moreover, under the proposed rule, transgender, non-binary and gender nonconforming people assigned female at birth whose gender marker is male or non-binary could be denied coverage for necessary care, such as pap smears, mammograms or emergency contraception. Similarly, transgender non-binary, and gender nonconforming people assigned male at birth whose gender marker is female or non-binary could be denied coverage for necessary care, such as a prostate exam.

By proposing to eliminate protections against discrimination based on transgender status and sex stereotyping, HHS is contradicting over 20 years of federal case law.¹

clear Supreme Court precedent. The overwhelming majority of courts that have been presented with the question of whether federally sex discrimination laws such as Section 1557 specifically cover anti-transgender discrimination have firmly ruled that they do.

The 2016 rule was finalized after substantial public consultation – more than 25,000 comments were received -- and years of deliberation. Our organization submitted comments in favor of inclusion of protections against discrimination based on sex stereotyping and gender identity. The 2016 rule is sound and well considered public policy, and should not be reversed.

II. Transgender Individuals Would be Especially Harmed by the Proposed Rule

Transgender, non-binary and gender nonconforming people already experience high rates of discrimination and harassment in health care. 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 past year. According to a 2018 study from the Center for American Progress, 23 percent had a provider intentionally mis-gender or use the wrong name for them, 21 percent had a provider use harsh or abusive language when treating them and 29 percent experienced unwanted physical contact from a health provider, such as fondling, sexual assault or rape.

Community Catalyst has supported efforts by LGBTQ+ groups across the nation to fight discrimination in health care, especially as experienced by transgender and gender non-conforming individuals. The 2016 HHS rule interpreting Section 1557 provided an
important step forward in fighting such discrimination. The proposed rule, by contrast, threatens to reverse this progress and instead sanction discrimination against transgender people by health providers and insurers.

There is much at stake. Our opposition to the proposed rule is motivated by the many personal stories we have heard about the pain and suffering individuals have experienced in trying to obtain needed care for the recognized medical diagnosis of gender dysphoria, as well as basic primary care that is provided routinely for cisgender patents. Depression, anxiety and even suicide can be the consequence of such denials. So, too, can injuries and even death from bigoted attacks experienced by individuals whose appearance that does not completely conform to traditional gender stereotypes.

One transgender individual described for us why gender-affirming surgery was so medically necessary, but reported having struggled to overcome obstacles posed by a discriminatory coverage denial by an insurer:

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\text{in addition to alleviating gender dysphoria, access to gender-affirming surgeries can reduce the risk of the harassment and violence that often lives underneath the depression and anxiety trans folks experience (i.e. part of the desire to look a certain way or “pass” is about security). For me, the denial exacerbated my internalized shame, depression and anxiety.}
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This individual appealed the insurance denial citing, in part, ACA section 1557 nondiscrimination provisions and succeeded in obtaining approval for the gender-affirming care:

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\text{Since accessing this form of care, my mental health has improved tremendously. I generally experience reduced social stress and anxiety as the world is more frequently affirming of my gender experience, and I have a greater sense of internal peace and joy.}
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LGBT care coordinators have reported that coverage denials are endemic in transgender care and nondiscrimination protections are only just beginning to be enforced:

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\text{“The process for getting health care is different for every trans person. What I can say is that a common thread through each of these processes are words like denial, exclusion, special exception and of course, appeals, appeals, appeals.”}
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With the support of Community Catalyst, the LGBT Task Force of Health Care for All NY held a series of listening sessions across the state in 2015 to assess the serious of discriminatory coverage denials being experienced by transgender New Yorkers. These sessions occurred prior to issuance of HHS’ 2016 rule implementing Section 1557 of the ACA, and thus provide a window into what types of discrimination could
once again be encouraged should HHS adopt its new proposed regulatory interpretation of Section 1557.

One testifier said that as an LGBT Care Coordinator, she found insurer coverage determination guidelines used arbitrary requirements that do not follow internationally recognized criteria for gender-affirming treatment and had a discriminatory effect:

“There was a huge list of qualifications that a person had to fit with in order to be awarded that coverage (for gender-affirming care). One that stuck out a lot for me was the need for a person to live in their (desired) gender for more than a year publicly before being awarded coverage for a gender-confirming surgery. That means, things like, going to school as the gender you identify with, going to work as the gender you identify with .... which is incredibly difficult. Living safely as their authentic selves means not being mis-gendered, not constantly getting “outed” as transgender. So what makes it easier to not constantly get “outed” as transgender? For that, many people need access to medically necessary procedures in which they affirm their gender and presentation. But of course, that is the original issue – they can’t have those because they don’t have access to those procedures until they do their requirement of living in their gender for a year. It’s what makes (their situation) even more unlivable.”

The 2015 Task Force report concluded that:

In many cases, transgender individuals are unable to wait to go through the appeals process and instead find other means to get care or go without.\(^7\),\(^8\) Many transgender individuals, even those with health insurance, resort to public fundraisers, medical loans and significant credit card debt to finance the cost of transition-related care because they do not have the ability to work through a lengthy appeals process.\(^9\)

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\(^7\) “A survey by the Transgender Law Center (Hartzell et al., 2009) of 646 transgender adults living in California, including 80 respondents over age 55, found that even when covered by insurance, 42 percent of respondents had delayed seeking care because they could not afford it, and 26 percent reported health conditions that had worsened because they postponed care.” The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding. National Academy of Sciences. 2011.

\(^8\) Transgender people face substantial discrimination due to social stigma around transgender identities and gender transition – waiting for gender affirming surgeries may not be an option as many transgender people are unsafe being visible without access to hormones or surgery. “Transgender people, particularly transgender women and transgender people of color, are also at particular risk of physical violence.” From Lombardi E, et al. (2002). Gender violence: Transgender experiences with violence and discrimination. J Homosex 42(1)

\(^9\) Without access to hormones or surgery, many transgender people are unable to perform typical daily functions as their gender dysphoria is too overwhelming; transition-related medical care helps remove secondary sex characteristics (such as beard, breast tissue, body hair, etc.) and ease gender dysphoria. Waiting for this care increases likelihood for depression, anxiety and other mental health concerns in transgender individuals. Bockting, et al. American Journal of Public Health, 2013.
Following issuance of the 2016 rule implementing Section 1557, the percentage of insurance plans that routinely exclude coverage for gender-affirming care began to drop. An Out2Enroll 2019 study of 37 states in the federal marketplace found that 94% of plans analyzed did not have blanket exclusions of transition-related care in 2019. Many insurers now include affirmative coverage language, in part due to the recognition of the fact that treatment for gender dysphoria is medically necessary and appropriate treatment.

Moreover, a number of states – including New York and Massachusetts, where the coverage denials outlined above took place – acted in accordance with Section 1557 to adopt their own state-level policies prohibiting health care discrimination against transgender patients and the entire LGBTQ community. The proposed rule would create confusion among health providers in such states and once again endanger access to care and coverage for transgender individuals. In communities without state-level nondiscrimination protections, health providers and insurers could believe they are free to deny coverage and care.

III. The Proposed Rule Impermissibly Attempts to Allow Pregnancy-Related Discrimination

The 2016 final rule made clear that sex discrimination under Section 1557 includes discrimination on the basis of pregnancy, false pregnancy, termination of pregnancy, or recovery therefrom, childbirth or related conditions. The proposed rule attempts to roll back these protections. Although HHS acknowledges in the preamble to this proposed rule that Title IX prohibits discrimination based on pregnancy, including termination of pregnancy, it refuses to state whether the Department would enforce those protections. While the scope of protection under Section 1557 is clear, without unambiguous implementing regulations and enforcement, illegal discrimination is likely to flourish.

The proposed rule would exacerbate already-existing barriers to accessing abortion care in a number of states, especially in the South and Midwest. Such barriers included mandated biased counseling (18 states) and waiting periods after receiving counseling before an abortion can be performed (27 states), as well as restrictions on use of Medicaid and even private insurance coverage (12 states) for abortion.10

We fear that the proposed rule would threaten the provision of prompt, medically-appropriate care for reproductive emergencies, such as termination of ectopic pregnancies and treatment for premature rupture of membranes, thereby endangering the health or life of a pregnant individual.

The proposed rule would have a disproportionate impact on pregnant people of color, especially those living in rural areas. These individuals already face significant barriers to

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accessing pregnancy-related and/or abortion care, such as a discrimination, harassment and refusals of care, and experience high rates of pregnancy-related complications. For example, Black women are 3-4 times more likely to die from pregnancy related complications than white women.

The proposed unlawful incorporation of Title IX’s exemptions would cause further harm to LGBTQ people, women of color and people with intersecting identities. For example, the proposed rule impermissibly tries to add Title IX’s religious exemption to Section 1557’s protection against sex discrimination, which could embolden providers to invoke personal beliefs to deny access to a broad range of health care services, including birth control, sterilization, certain fertility treatments, abortion and gender-affirming care. Similarly, the Administration once again attacks abortion access by impermissibly incorporating the “Danforth Amendment,” which carves out abortion care and coverage from the ban on discrimination of sex in the education context. Both attempts to incorporate exemptions from other laws violate the plain language of Section 1557.

IV. The Proposed Rule Impermissibly Attempts to Amend Unrelated Regulations to Exclude Sexual Orientation and Gender Identity Protections

The 2016 final rule did not affect other HHS health care regulations. The proposed rule attempts to erase all references to gender identity and sexual orientation in all HHS health care regulations. If implemented, this rule would eliminate express prohibitions on discrimination based on gender identity and sexual orientation from regulations that govern a range of health care programs, including private insurance and education programs. This could result in less health care and poorer health outcomes for LGBTQ people across the country.

For example, under the proposed rule, Programs of All-Inclusive Care for the Elderly (“PACE”) organizations, which serve people ages 55+, could discriminate against LGBTQ people.11 There are more than 3 million LGBTQ people age 55+ in the U.S. That number is expected to double within the next 20 years.12 Many older LGBTQ adults already feel reluctant to discuss their sexual orientations and gender identities with health providers due to fear of judgment and/or substandard care.13 The proposed rule would only further discourage older LGBTQ adults from sharing information that may be relevant to the health services they need.

V. The Proposed Rule Impermissibly Attempts to Eliminate Language Access Protections

The proposed rule would illegally pull back on language access protections for people with Limited English proficiency (“LEP”) by proposing to roll back requirements for the inclusion of taglines on significant documents and remote interpreting standards and by proposing to eliminate recommendations that entities develop language access plans.

Discrimination on the basis of national origin, which encompasses discrimination on the basis of language, creates unequal access to health care. Over 25 million Americans are limited English proficient. An estimated 19 million LEP adults are insured. Language assistance is necessary for LEP persons to access federally-funded programs and activities in the health care system.

For LEP individuals, language differences often compound existing barriers to access and receiving appropriate care. LEP often makes it difficult for many 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 nondiscrimination notice, taglines and language access plan language in the 2016 Final Rule were not justified by need, were overly burdensome and created inconsistent requirements. The notice requirement is consistent with the long history of civil rights regulations requiring the posting of notice of rights. The notice is not redundant as OCR created the option of using one consolidated civil rights notice to minimize burden on covered entities. Without the notice, members of the public will have limited means of knowing that language services and auxiliary aids and services are available, how to request them, what to do if they face discrimination, and their right to file a complaint.

Taglines are well supported by existing federal and state regulations, guidance and practice. Taglines 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, and are grounded in OCR’s experience that failures of communication based on the absence of auxiliary aids and services and language assistance services raise particularly significant compliance concerns under Section 1557, as well as Section 504 and Title VI.”

We oppose removing all references to language access plans because under the 2016 Final Rule, they are voluntary, not required by law and only a factor to be considered. We oppose changes in the NPRM that would shift the inquiry of meaningful access away from the individual LEP person to that of the entity, as doing so would weaken the standard.
VI. The Proposed Rule Impermissibly Attempts to Eliminate Prohibitions on Discrimination in Insurance Plan Benefit Design and Marketing

Before the ACA, people with serious and/or chronic health conditions were often denied health insurance coverage or paid high prices for substandard plans with coverage exclusions, leaving many people unable to afford the health care they needed. Under the ACA, insurers can no longer charge higher premiums or deny coverage for people with pre-existing conditions. These protections have been lifesaving for many people.

Under the 2016 final rule, covered entities are prohibited from designing benefits that discourage enrollment by persons with significant health needs. For example, insurers are prohibited from placing all or most prescription drugs used to treat a specific condition, such as HIV prescriptions, on a plan’s most expensive tier. Additionally, covered entities are prohibited from using discriminatory marketing practices, such as those “designed to encourage or discourage particular individuals from enrolling in certain health plans.” The proposed rule improperly attempts to eliminate these prohibitions.

The proposed rule will have a disproportionate impact on LGBTQ people and people of color who live with disabilities and/or chronic conditions. Due to systemic barriers to health care and the stress of stigma and discrimination, people of color and LGBTQ people, and especially gay, bisexual, and queer men of color and transgender women of color, are at a higher risk of developing chronic conditions and have a higher prevalence of disabilities.

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

The 2016 final rule that implemented Section 1557 applies to all health programs and activities that receive federal financial assistance from the Department, all health programs and activities administered by the Department, and state-based marketplaces. The 2016 final rule defines health programs and activities to include all operations of an entity receiving federal financial assistance that is principally engaged in the provision or administration of health-related services or health-related insurance coverage.

The proposed rule attempts to reduce the number of health insurance plans that are covered by claiming that if the issuer of a health plan is “not principally engaged in the business of providing health care (as opposed to health insurance),” only its Marketplace

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plans would be covered and any plans it offers outside the marketplace would not be subject to Section 1557.”[1] Additionally, the proposed rule improperly attempts to narrow that application of Section 1557’s protections to only the portion of a health care program or activity that received federal financial assistance. These changes unlawfully narrow the scope of Section 1557’s application. 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, or under any program or activity that is administered by an Executive Agency or any entity established under this title (or amendments).” 42 U.S.C. § 18116(a).

The proposed change would have significant consequences, particularly for consumers who purchase short-term limited duration insurance (“STDLI”), which would appear to be exempted from non-discrimination requirements under this rule, since these specific plans do not receive federal financial assistance or provide health care services. Short-term plans have been found to discriminate against consumers based on gender, age, and disability, such as by refusing to cover maternity care or charging women more than men.[17]

VIII. The Proposed Rule Impermissibly Attempts to Undermine Notice and Enforcement Requirements and Remedies

The proposed rule also impermissibly seeks to limit the enforcement mechanisms available under Section 1557 for patients who have experienced discrimination, including by attempting to eliminate notice and grievance procedure requirements, private rights of action, opportunities for money damages, and by claiming that the remedies and enforcement mechanisms for each protected characteristic (race, color, national origin, age, disability or sex) are different and limited to those available under their referenced statute.

As a result, the proposed rule would create a confusing mix of legal standards and available remedies under a single law, and could limit claims of intersectional discrimination, going against the text and intent of Section 1557. Ultimately, the proposed rule will make it harder for those who are discriminated against to access meaningful health care and to enforce their rights.


IX. Conclusion

Contrary to the intent of the Affordable Care Act, of which Section 1557 is a crucial provision, this proposed rule would lead to diminished coverage and significant barriers to care for people who already struggle to obtain needed health care. It would particularly harm transgender people and the entire LGBTQ community; people seeking reproductive health care, including abortion services; individuals with LEP, including immigrants; those living with disabilities and people of color. Moreover, this rule would embolden compounding levels of discrimination against those who live at the intersection of these identities. The proposed rule is dangerous and contravenes the plain language of Section 1557, specifically, and the ACA broadly.

For the reasons detailed above, HHS and CMS should not finalize the proposed rule. We urge you to withdraw it entirely.

Thank you for the opportunity to submit comments on the proposed rule. Please do not hesitate to contact Lois Uttley, Women’s Health Program Director for Community Catalyst, at luttley@communitycatalyst.org should you desire further information.

Sincerely,

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Community Catalyst