FAMILIESUSA
THE VOICE FOR HEALTH CARE CONSUMERS

August 13, 2019

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

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

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

Submitted electronically via Regulations.gov

Dear Secretary Azar and Mr. Severino:

Families USA, a leading national voice for health care consumers, is dedicated to the achievement of high-quality, affordable health care and improved health for all. We seek to make concrete and tangible improvements to the health and health care of the nation – improvements that make a real difference in people's lives. In all of our work, we strive to elevate the interests of children and families in public policy to ensure that their health and well-being is foremost on the minds of policymakers. We appreciate the opportunity to comment on this notice of proposed rulemaking.

The proposed rules on Section 1557 will harm families with limited English speaking proficiency, adults and children with disabilities, and people subject to many forms of discrimination. We urge you to withdraw this proposed rulemaking. The proposed rules will undermine important civil rights even though the Affordable Care Act worked to clarify that those rights apply in health care. HHS underwent an extensive process to develop regulations for Section 1557, including a Request for Information, proposed rule, and final rule. HHS considered more than 24,875 public comments submitted for the 2016 rule. In rewriting this rule, HHS is ignoring many of those comments; these rules do not adequately consider consumer protections and should be withdrawn.

As National Health Law Program is explaining in its comments, HHS should not take action to revise rules based on the preliminary injunction of a federal District court in *Franciscan Alliance v. Azar.* That case is not settled, and numerous other court cases speak to the substantive requirements and enforcement mechanisms of 1557 as consistent with rules currently in place. Moreover, the proposed changes will be harmful to the many people who face health care disparities. For example, at a time when maternal mortality has risen and is notably higher among black women and among American Indian/Alaska Native

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women than among white women,[1] eliminating nondiscrimination protections would set our nation's health backwards.

Scope of 1557

Section 1557 clearly covers "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 entity or any entity established under this title…." The proposed rule appears to narrow this so that, for example, only marketplace plans and not plans offered by the same issuer off of the marketplace would be covered. This is unlawful and goes against Congress's clear intent that one set of rules and protections apply to all health insurance under Title I. Qualified health plans, whether offered on or off exchange, must comply with standards set forth under Title I. Amendments made to the public health act under Title I apply to "group health plans" and to "a health insurance issuer offering group or individual coverage." It would make no sense to allow an off-marketplace plan, nor another health insurance product offered by that issuer, to discriminate based on gender, disability, sex, or race; nor to discriminate based on age (other than allowable age rating) and doing so would go against the intent and provisions of the ACA.

The proposed rule also creates confusion about whether plans sold on marketplaces that are not QHPs, such as stand-alone dental plans, are subject to nondiscrimination requirements. There are huge disparities in oral health.[2] Nondiscrimination protections are one of many needed tools to help ensure access.

Rules over the last few years have significantly expanded the sale of short term limited duration insurance in ways not contemplated by the Affordable Care Act. Consumers in these plans already lack significant protections. Companies that issue marketplace plans must be bound by nondiscrimination rules in all of their products; otherwise, they will seek to undermine the marketplace by steering consumers into short term plans that use a wide range of discriminatory practices to avoid populations that may be costly.

Similarly, health programs and health facilities that receive federal funds cannot be permitted to wall off parts of their programs, allowing some parts to discriminate and others not. There is no coherent way for them to do that. Patients should not have to discern whether they are in a wing of a facility or a part of a program where they have basic protections from discrimination or not.

Notice and Language Access

The proposed rule proposes to eliminate notice and tagline requirements as "confusing and costly". However, without notice, consumers would not know their rights or be able to seek relief and

[1] CDC Pregnancy Mortality Surveillance System, https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pregnancy-mortality-surveillance-system.htm.
[2] These are noted by CDC on https://www.cdc.gov/oralhealth/oral_health_disparities/index.htm, along with disparate abilities to "get and keep dental insurance."

enforcement if their rights were violated. It is impermissible to eliminate notice that is crucial to the working of the law.

Over 60 million US residents speak a language other than English at home, and about 16 million of these say they speak English "less than Very Well".[3] These include older adults and people with disabilities for whom it is unrealistic to expect that they will become proficient in English, and others who may at some point gain English proficiency but need health care meanwhile. It is essential to their health, and often to the public's health, that LEP individuals are able to access interpreters who can explain health care decisions and instructions. LEP individuals also must be able to understand and be able to respond to important notices concerning their coverage and potential liability for health care expenses – such notices have financial implications for the patient, the patient's family, the providers, and the insurer.

Though the rule retains some requirements in 92.101 and 92.102 for language assistance and for communication with individuals with disabilities using "health programs or activities", these provisions are effectively undermined by the lack of notice and by the overly broad enforcement discretion.

The proposed rule mentions the cost and paperwork of providing notice as a reason for eliminating notice requirements. It may be possible to design an effective means of providing notice that requires less paper[4] – but doing so would require consumer testing, a specific comment period about the proposed alternative, and a phase in period, none of which is provided in this proposed rule.

States and localities that have their own language access requirements impose some uniformity on public notice. For example, in the District of Columbia, uniform notices are posted in public places, such as a public office or the check-out counter at the library, that allow LEP individuals to point to their language to request an interpreter and important notices must be translated into languages spoken by significant percentages of residents.[5] To effectively reach LEP individuals, health programs and health insurers must similarly be subject to uniform requirements that are known by the public; however, the proposed federal rule impermissibly withdraws federal requirements and leaves it to the discretion of health care programs to determine how they will notify participants of their rights; further, depending on how the rule is interpreted, it either eliminates entirely or at best, creates ambiguity about whether entities such as insurers would provide notice in appropriate languages and when.

The proposed rule harmfully and impermissibly attempts to narrow the definition of sex discrimination

The proposed rule would have a disproportionate and harmful effect on LGBTQ people, especially transgender, nonbinary, and nongender-conforming people. Current rules make clear that discrimination based on sex includes discrimination based on sex stereotyping or gender identity. These

[3] U.S. Census, Detailed Languages Spoken at Home and Ability to Speak English for the Population 5 years and over: 2009-2013, https://www.census.gov/data/tables/2013/demo/2009-2013-lang-tables.html.

[4] For example, according to this article, UNICEF appears to be experimenting with development of a translation symbol; perhaps that might be adopted in other contexts over time: http://access.ecs.soton.ac.uk/blog/symboldictionary/

[5] DC Office of Human Rights, Language Access Act (see regulations, toolkit, related materials on https://ohr.dc.gov/service/language-access-program-information-portal, accessed August 7, 2019).

current rules are consistent with two decades of case law.[6] The proposed rule illegally purports to allow a health care provider to refuse to treat someone because of their gender identity. Moreover, under the proposed rule, the health care provider could refuse to treat a person for *any* health condition based on the patient's gender identity – the provider might refuse all treatment to the patient for *any* health care, or refuse necessary care such as a pap smear that they routinely provide to other patients, or refuse gender-affirming care.

Trans-gender, nonbinary people already experience high rates of discrimination and harassment in health care. The 2015 Transgender Survey, with almost 28,000 respondents, found that one-third of respondents who had seen a health care provider had at least one negative experience, such as being verbally harassed or refused treatment due to being transgender, and that an additional one quarter of respondents did not seek health care due to fear of harassment.[7] Discrimination and health disparities were compounded for trans people of color.

Current 1557 rules begin to address such discrimination and this is supported by major medical groups including the American Medical Association, the American Academy of Pediatrics, the American Psychological Association, the American Psychiatric Association, and others.[8] Proposed rules would roll back gains and illegally permit further discrimination. We do not know of any other contexts in which health care can be withheld from someone based on their identity or appearance or personal characteristics – this would set an extremely dangerous precedent.

The proposed rulemaking also rolls back a number of other long-standing rules that prohibit discrimination on the basis of gender and identity by eliminating those terms: 45 CFR 155.120 (c)(1)(ii) and 155.120 (j)(2), 45 CFR 147.104(e), 45 CFR 156.1230(b)(3), 42 CFR 460.98 (b)(3) and 460.112(a), 42 CFR 438.(d)(4), 438.206(c)(2) and 440.262. These rules are outside the scope of this rulemaking and not under the jurisdiction of the Office for Civil Rights. HHS has not offered any analysis of their impact. These changes are bound to sew confusion and result in discrimination – they will impact the ability of LGBTQ people to receive care in PACE programs, and could result in confusion about whether navigators and exchanges must provide information to LGBTQ people – which certainly has nothing to do with the controversies about religious conscience in the cases cited in this rulemaking.

The proposed rule improperly and harmfully rolls back nondiscrimination protections based on sex, including pregnancy status and termination of pregnancy

Discrimination on the basis of pregnancy status or termination of pregnancy is clearly prohibited under regulations pursuant to Title IX, rules promulgated in 1975 and amended in 2005 (45 CFR 86.40). Title IX nondiscrimination protections are explicitly incorporated into Section 1557. The proposed rule seeks to unlawfully incorporate the Danforth Amendment, carving out abortion care and coverage from the ban on discrimination. These changes could put women at risk of being denied emergency contraceptives and prenatal care, endangering their overall health. They could put women who have had an abortion at

[6] National Center for Transgender Equality, "Federal Case Law on Transgender People and Discrimination," https://transequality.org/federal-case-law-on-transgender-people-and-discrimination
[7] https://www.ustranssurvey.org/
[8] Statements available on https://protecttranshealth.org/why-this-matters/.

risk of being denied all care by the only providers available in a rural area. We disagree with these proposed changes.

The proposed rule impermissibly and harmfully attempts to eliminate prohibitions on discrimination in insurance plan design

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 to treat a specific condition on a plan's most expensive tier. This has helped patients with conditions ranging from HIV to Multiple Sclerosis. Prior to the rule, certain insurers placed all drugs to treat HIV, including generics, on the highest tier making it difficult or impossible for patients with HIV to afford their drugs.[9] Additionally, covered entities are prohibited from using discriminatory marketing practices that are designed to encourage or discourage particular individuals from enrolling in certain health plans. The proposed rule improperly and impermissibly attempts to eliminate these provisions by entirely eliminating 92.207. The proposal cites other rules, predating the ACA, regarding discrimination – but these rules appear to be consistent in concept without clearly explaining their application to health plans as does 92.207. Elimination of this provision will disproportionately impact people with disabilities and LGBTQ people.

The proposed rule impermissibly and harmfully limits remedies

We believe that HHS incorrectly limits the remedies available under Section 1557 in the proposed changes to § 92.301 (newly designated § 92.5). One of the goals of Section 1557 was to build and expand on prior civil rights laws such that individuals seeking to enforce their rights would have access to the full range of available civil rights remedies and not be limited to only the remedies provided to a particular protected group under prior civil rights laws. This is why Section 1557 expressly provides individuals access to any and all of the "enforcement mechanisms provided for and available under" the cited civil rights statutes, regardless of the type of discrimination. The proposed rule makes it harder and more complicated to address prohibited discrimination. Access to the courts is crucial for individuals seeking to enforce their rights. HHS should retain current § 92.301.

For all of the above reasons, we urge you to withdraw this proposed rulemaking.

Thank you for the opportunity to submit these comments. If you have any questions, please contact Cheryl Fish-Parcham at CParcham@familiesusa.org or 202-628-3030.

Respectfully submitted,

Cheryl Fish-Parcham
Director of Access Initiatives at Families USA

[9] Michelle Andrews, Kaiser Health News, Some Plans Skew Drug Benefits to Drive Away Patients, Advocates Warn, July 2014. Available online at https://khn.org/news/some-plans-skew-drug-benefits-to-drive-away-patients-advocates-warn/.