November 9, 2015

Ms. Jocelyn Samuels
Director, Office for Civil Rights
U.S. Department of Health and Human Services
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue S.W.
Washington, DC 20201

ATTN: 1557 NPRM (RIN 0945-AA02)

Dear Ms. Samuels:

The Center for Public Policy Priorities (CPPP) respectfully submits the following comments to the Department of Health and Human Services (HHS), Office of Civil Rights (OCR), in response to the notice of proposed rulemaking (NPRM) concerning § 1557 of the Patient Protection and Affordable Care Act, released on September 9, 2015.

CPPP is a nonpartisan, nonprofit 501(c)(3) policy institute established in 1985 and committed to improving public policies to better the economic and social conditions of low- and moderate-income Texans. Improving access to health care for Texans has been at the core of our mission and activities since our founding 30 years ago.

CPPP appreciates the opportunity to provide comments on the proposed rule on Nondiscrimination in Health Programs and Activities. We strongly support the proposed rule's nondiscrimination protections in all federally funded, supported and conducted health programs and activities. This rule is a very important step toward strengthening protections for people who have often been subject to discrimination in our health care system and reducing health care disparities in our communities.

We fully endorse the comments seeking to support strong nondiscrimination protections submitted by the following organization: National Health Law Program (NHelP), National Immigration Law Center (NILC), and Community Catalyst.

The goal of these comments is to strengthen the proposed rules for § 1557 as it relates to low- and moderate-income families.

Applicability and Scope
The following recommendations seek to broaden the scope and application of the proposed rule drawing from existing authority, as well as limit exemptions that would weaken the impact of the proposed rule.

1. **We urge HHS to explicitly apply the final rule to *all* federally-administered health programs and activities, and health programs and activities any part of which receive federally funding – not just those administered by HHS and Title I of the ACA (§ 92.2)**. Such broad

application is permitted by the text of Section 1557 of the ACA. This will centralize oversight for this rule in the OCR within HHS, which specializes in discrimination in health, rather than require separate enforcement offices across disparate agencies.

2. **We urge HHS to make the scope of the application of Section 1557 clearer by defining the term "health."** HHS can use the widely referred to World Health Organization (WHO) definition, in which "health" is not just the absence of disease, but also as an individual's or a population's physical, mental or social well-being.[1]

3. **We ask HHS to strengthen nondiscrimination protections for immigrants by clarifying that it has explicit authority under Section 1557 to enforce the principles found in the Tri-Agency Guidance.**[2] These principles include protecting confidentiality and limiting the collection, use and disclosure of personally identifiable information—such as Social Security numbers, citizenship or immigration status information—for non-eligible/non-applicant family members in families whose members are of mixed-immigration status.[3]

4. **We urge HHS not to use this regulation to add any additional religiously-based exemptions to those already in effect through the protections afforded by provider conscience laws,**[4] **the Religious Freedom Restoration Act,**[5] **or regulations issued related to preventive health services.**[6] We believe these existing federal protections are sufficient for health care refusals based on religious exemptions. Religious exemptions authorize health care refusals that have very real and devastating consequences, especially for women. We strongly oppose any new exemption that would permit discrimination based on religious views against any person, especially women, people with disabilities, or LGBT people.

5. **We oppose continuing the exclusion of Medicare Part B providers from coverage under Section 1557.**

Language Access

We strongly support the rule's specific requirements to ensure meaningful access for individuals with limited English proficiency. In particular, we support the definition of qualified interpreter, and we suggest including a definition of a qualified translator that mirrors the competency requirements for qualified interpreters.

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[1] Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 8 April 1948.

[2] The Tri-Agency Guidance limits inquiries regarding citizenship, immigration status and Social Security numbers from family members who are not applying for assistance. Health and Human Services and Department of Agriculture, Policy Guidelines Regarding Inquiries into Citizenship, Immigration Status and Social Security Numbers in State Application for Medicaid, State Children's Insurance Program (SCHIP), Temporary Assistance for Needy Families (TANF), and Food Stamp Benefits.

[3] Dept. Health and Human Services and Department of Agriculture, Policy Guidelines Regarding Inquiries into Citizenship, Immigration Status and Social Security Numbers in State Application for Medicaid, State Children's Insurance Program (SCHIP), Temporary Assistance for Needy Families (TANF), and Food Stamp Benefits.

[4] See, e.g., 42 U.S.C. 300a–7; 42 U.S.C. 238n; Consolidated and Continuing Appropriations Act 2015, Pub. L. 113–235, 507(d) (Dec. 16, 2014).

[5] 42 U.S.C. 2000bb–1.

[6] See 45 CFR 147.131.

Further, we strongly support including specific thresholds for translating written documents to ensure minimum standards exist that would directly aid evaluating compliance and enforcement. We also support requirements regarding taglines, but we are concerned that this national threshold will fall short of meeting the needs of local demographics. We recommend that covered entities include taglines in the top 15 languages in their state/service area rather than the proposal to only include the top 15 languages nationally. It is possible that in some communities in Texas, the top 15 languages nationally will not be useful for informing local limited English proficient communities.

We also recommend that the rule require covered entities to translate vital documents for each language group that makes up 5 percent or 1,000 persons, whichever is less, of the population eligible to be served, or likely to be affected by the program, or recipient in the service area. This numeric threshold is already employed in other federal agency policy guidance, with some programs and agencies employing even lower thresholds. We have heard several accounts of consumers in Texas being unable to get needed health insurance documents in Spanish, even in areas of the state where Spanish is as prevalent as English.

Finally, as stated above, we oppose continuing the exclusion of Medicare Part B providers from coverage under Section 1557.

Sex Discrimination

We support the rule's new prohibitions on discrimination on the basis of sex and the definition included (92.206 and 92.207(b)). We support the rule's inclusion of sex stereotyping and gender identity in the definition of sex discrimination. We strongly urge HHS to include sexual orientation – which means homosexuality, heterosexuality or bisexuality-- into this definition "on the basis of sex" in § 92.4.

Women's access to reproductive health care is a matter of sex equality, and health care refusals (also known as conscience clauses) involving reproductive health care and services constitute impermissible sex discrimination. As we noted above, health care refusals that have very real and devastating consequences, especially for women. We strongly oppose any new exemption that would permit discrimination based on religious views against any person, especially women, people with disabilities, or LGBT people.

Disability Issues

We strongly support the provisions requiring effective communication for individuals with disabilities and accessibility standards, including the requirements for websites and electronic and information technology. However, we are concerned about waiting 18 months past the publication of the final rule for compliance with standards when the ADA has required such accessibility for over 20 years.

We strongly recommend that the definition of "disability" in § 92.4 should explicitly include the non-exhaustive list of health conditions that qualify as disabilities under the Americans with Disabilities Act (ADA) Amendments Act of 2008,[7] because these conditions significantly limit major life activities

[7] 29 CFR Part 1630 implementing these amendments made any condition a "disability" that substantially limits major bodily functions, such as functions of the immune system, special sense organs, and skin; normal cell growth; and digestive,

(including major bodily functions): Deafness, blindness, intellectual disabilities, missing limbs, autism, cancer, cerebral palsy, diabetes, epilepsy, HIV, multiple sclerosis, muscular dystrophy, major depressive disorder, bipolar disorder, post-traumatic stress disorder, obsessive compulsive disorder, and schizophrenia.

We also recommend the rule require basic accessibility for medical equipment now while recognizing more specific standards from The Access Board will be provided at a later date.

Data Collection

One tenet of ensuring compliance with nondiscrimination requirements is to ensure strong data collection. Having accurate data ensures that covered entities have the needed information to determine how to provide language services and auxiliary aids and services. We urge HHS to add specific demographic data collection requirements to the rule for all covered entities. Covered entities should be required to collect data on race, ethnicity, language, sex, gender, gender identity, sexual orientation, disability status, and age. However, we strongly discourage the collection of immigration status information as part of any collection of demographic information by any entity covered under § 1557 unless doing so is required to determine eligibility for program participation, such as for Medicaid, CHIP and the exchanges. The collection of immigration status information, especially when made mandatory, may deter immigrants and persons in mixed-immigration status families from seeking health-related services, raising civil rights concerns rather than assisting an agency in compliance with § 1557 and civil rights laws.

Covered entities should be required to assess (and update their assessments) of the population they serve and are eligible to be served so that they can appropriately plan how to meet the needs of their clients/patients. HHS should provide guidelines as to how to conduct an assessment and what data may be readily available to covered entities.

Benefit Design and Marketing

We also strongly support nondiscrimination requirements to benefit design and marketing practices and recommend that they be strengthened in the following ways:

- We recommend HHS define "benefit design" to include, but not be limited to, cost-sharing, drug formularies and tiers, provider networks including any tiers, limits on coverage of certain services by age or condition, wellness programs, prior authorization and other utilization management or medical management techniques. As an example, health plans should not be permitted to put all the medications required to treat a condition or ailment on the highest formulary tier. If they do, they should be subject to Section 1557's enforcement provisions.

- Define "marketing practices" as the activities of any covered entity or program designed to encourage individuals to enroll in or seek services from a covered entity.

- Add language that plans that do not include all or nearly all of a certain specialist provider type in the plan network or network tier are discriminatory. Plans have been shown to completely exclude

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genitourinary, bowel, bladder, neurological, brain, respiratory, circulatory, cardiovascular, endocrine, hemic, lymphatic, musculoskeletal, and reproductive functions.

certain providers at alarming rates, which discriminates against those with disabilities or other classes requiring access to these providers.[8]

- Include as regulatory language the following examples of insurance practices that are discriminatory on the basis of disability:
  - Placing all or nearly all medications or services that treat a certain condition on the highest cost-sharing tiers.
  - Not covering certain medications that are recommended in treatment guidelines.
  - Imposing arbitrary or unreasonable medication management tools such as requiring prior authorizations and/or step therapy for all or nearly all medications that treat a certain condition.

- Adopt a standard way of addressing cost-based discrimination in the final rule. A cost-based discrimination standard would likely have to define unaffordability – as the Internal Revenue Service (IRS) had already done to define unaffordability for the purposes of premium assistance.[9] An "unaffordable" medication or service could become discriminatory if there was no lower-cost, but similarly efficacious drug or service available to an individual protected by Section 1557.

Enforcement

We strongly support Section 1557's inclusion of both administrative and judicial remedies for discrimination. In particular, we recommend that the rule better reflect the statutory language by clarifying and strengthening the judicial enforcement opportunities and by directly recognizing that Section 1557 permits judicial claims for disparate impact discrimination. Further, as the statutory language of Section 1557 authorized the Secretary of HHS to promulgate regulations, as noted above, we recommend the proposed rule apply to **all** federally funded, supported and conducted activities and not just those of HHS.

Thank you for consideration of our comments on this important rule. We appreciate the great strides HHS has undertaken to advance the requirements of nondiscrimination. The proposed rule should be even stronger to better protect all people at risk of discrimination in health coverage or care. There is no excuse for discrimination in health care using federal funds or operated by federal agencies. If you have any questions regarding these comments, please contact Stacey Pogue, senior policy analyst with the Center for Public Policy Priorities at pogue@cppp.org or (512) 320-0222 x 117.

Sincerely,

Stacey Pogue
Senior Policy Analyst

[8] Dorner SC, Jacobs DB, Sommers BD. Adequacy of outpatient specialty care access in marketplace plans under the Affordable Care Act. *JAMA*. 2015;314(16):1749-1750.

[9] Internal Revenue Service, Department of the Treasury. 26 CFR Parts 1 and 602. Health Insurance Premium Tax Credit. Available from: http://www.gpo.gov/fdsys/pkg/FR-2012-05-23/pdf/2012-12421.pdf