August 10, 2019

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

RE: HHS Docket No. HHS-OCR-2019-000, RIN 0945-AA11,
Comments in Response to Section 1557 NPRM

Dear Mr. Severino:

Thank you for the opportunity to submit comments on behalf of the Center for Public Representation (CPR) regarding the Department of Health and Human Services (HHS) notice of proposed rulemaking (NPRM) on Section 1557 of the Affordable Care Act. CPR is a national legal advocacy organization that promotes the full inclusion of people with disabilities in all aspects of life, and we write to express our strong opposition to the proposed rule. Through policy advocacy and litigation, CPR works to ensure that people with disabilities can access health care and other services they need to live and participate in their communities. Across the country, we work with people with disabilities who struggle to access health care to which they are legally entitled. We strongly oppose the NPRM’s provisions which seek to eliminate and otherwise limit civil rights protections and make accessing health care even more difficult for people with disabilities and people from other marginalized communities.

Section 1557 prohibits discrimination in health care on the basis of race, color, national origin, sex, age, and disability. We strongly oppose the NPRM provisions which seek to eliminate and limit the law’s protections for people with disabilities and chronic health conditions, as well as individuals who are limited English proficient, LGBTQ persons, and persons needing reproductive health services.

The proposed rule would severely undermine the well-established rights of individuals with disabilities, negatively impacting people with disabilities and chronic conditions, their families, and communities. The proposed rule lacks any reasonable basis for altering settled law and increases the likelihood of discrimination against people with disabilities in the critical area of healthcare financing and access to care. We urge that the proposed rule be withdrawn in its entirety.
Section 1557 and its implementing rules are critical because people with disabilities are routinely discriminated against in the provision of health care. We are disappointed that HHS now seeks to weaken Section 1557 despite the extensive process that HHS underwent to develop regulations for Section 1557, including a Request for Information, proposed rule, and final rule.\(^1\) HHS considered more than 24,875 public comments submitted for the 2016 rule.\(^2\) It is arbitrary and capricious for HHS to reopen this rule and ignore the reasoned process HHS has already undertaken.

CPR urges HHS to withdraw the rule and reject all of the proposed changes in the rule that would limit access and the rights of people with disabilities and chronic health conditions. CPR makes the following specific comments in response to the proposed changes:

(1) Retain the Current Definition of a “Covered Entity”

We oppose the proposed changes to the current definition of a “covered entity.” The proposed rule seeks to radically narrow the scope and applicability of Section 1557, contrary to the plain meaning of the statute. Congress made clear in Section 1557 that if one part of an entity receives federal financial assistance, the entire entity should be covered. It also clearly intended Section 1557 to address discrimination in health insurance. Narrowing the scope of coverage, particularly to exclude health insurance, would eliminate one of the major areas where people with disabilities experienced the most significant health care discrimination and would eliminate one of the most important protections of Section 1557.

(2) Retain Current Notice Requirements for Covered Entities

We disagree with HHS’ proposal to delete the current requirement that covered entities provide notice, with every significant communication to individuals, that they do not discriminate based on disability or other prohibited grounds; that they provide auxiliary aids and services for people with disabilities, including qualified interpreters and information in alternate formats; and how to obtain those auxiliary aids and services. Without the notice, members of the public will have limited means of knowing that auxiliary aids and services are available, how to request them, what to do if they face discrimination, and their right to file a complaint. As HHS itself notes in the proposed

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rule, “repealing the notice of nondiscrimination requirement may result in additional societal costs, such as decreased utilization of auxiliary aids and services by individuals with disabilities due to their reduced awareness of such services.” We agree and therefore object to removing this requirement.

(3) Retain Current Language Prohibiting Discrimination by Insurance Companies

We urge HHS to retain strong, clear language prohibiting insurance companies from discriminating on the basis of race, color, national origin, sex, age, or disability in a number of areas, including marketing plans, designing benefits, coverage claims, or imposing additional costs. These protections are especially important for people with disabilities and those with serious or chronic conditions. Eliminating this regulatory provision could result in health insurers illegally excluding important benefits, designing their prescription drug formularies in a way that limits access to medically necessary care, or cherry-picking healthier enrollees through marketing practices. It may make it harder for people who experience discrimination to enforce their rights through administrative and judicial complaints.

(4) Retain Communication Access and Aids for Individuals with Disabilities

We urge HHS to retain the language in the 2016 Final Rule regarding effective communication for individuals with disabilities. In the proposed rule, HHS changes the definition of auxiliary aids and services and does so without explanation. HHS claims to import the definition of auxiliary aids and services from the regulations for Title II of the Americans with Disabilities Act but deletes “[a]cquisition or modification of equipment and devices; and [o]ther similar services and actions” from the list of examples of aids and services. This could create confusion, as it takes what is now a clearly illustrative list and implies that it is exhaustive. HHS should retain the definition of "auxiliary aids and services" from the 2016 final rule. Furthermore, we oppose any proposal to exempt entities with 15 or fewer employees from the requirement to provide effective communication. In some areas of the country, this could effectively bar access to many providers, including specialists who are essential to providing high-quality health care to individuals with disabilities and chronic health conditions.

(5) Retain Current Requirements for “Reasonable Modification” and “Undue Hardship”

We assert that HHS should not change the current requirements to provide “reasonable modification,” and import exemptions for “undue hardship,” The substitute language is from regulations related to employment, and is unnecessary, ill-fitting, and inappropriate for a health care context. Exemptions should not exist regarding elevators in multistory buildings, as this is likely to severely limit access to necessary medical care.

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4 84 Fed. Reg. 27868
5 84 Fed. Reg. 27867
Retain Section 1557's Existing Enforcement Provisions

We oppose the proposed changes that would severely limit the remedies available to under Section 1557. 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 current regulations also clarify that victims of disparate impact discrimination have a private right of action to challenge that discrimination in federal district court. We oppose the proposed rule’s elimination of provisions recognizing a private right of action and attempts to preclude both disparate impact and intersectional claims.

Withdraw the Proposed Rule on the Basis that Its Provisions Strip Protections Against Discrimination for Marginalized Groups, Including Individuals with Limited English Proficiency and LGBT Individuals

Lastly, we note that people with disabilities, like all people, have intersectional identities and that the anti-discrimination mandate in 1557 is designed to prohibit discrimination based on a single identity as well as the intersection of two or more identities such as race and disability, age and disability, or sex and disability. The proposed rule seeks to strip protections from persons with limited English proficiency, LGBTQ individuals, and women. We stand in solidarity with other marginalized groups in objecting to this proposed rule.

● Retain Protections for Individuals with Limited English Proficiency

We strongly oppose the proposal to eliminate the 1557 rule's nondiscrimination notice, taglines, and language access plan provisions. These provisions are key to ensuring the individuals who are limited English Proficient (LEP) -- including many with disabilities -- can access care and services, receive important healthcare information in a language they understand and are informed of their rights and how to enforce them. The risks for people with disabilities who are unable to access health care due to language or other barriers are even greater because many people with disabilities have complex health care needs. Health care information is complicated and can only be communicated effectively in an individual's primary language.

● Retain Existing Definitions To Ensure LGBT Individuals are Protected

We strongly oppose the proposed rule’s elimination of the definitions of sex, gender identity, and references to sex stereotyping. The current regulations make clear that the law’s prohibition on discrimination on the basis of sex includes discrimination on the basis of gender identity and sex stereotyping. The rules’ protections for transgender individuals -- including the many people with disabilities who are transgender -- include

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6 45 C.F.R. § 92.4
requiring providers to treat individuals consistent with their gender identity and prohibiting health plans from denying medically necessary care such as a prostate exam for a trans woman or a hysterectomy for a trans man.\textsuperscript{7}

By proposing to eliminate these definitions and provisions providing explicit protections for transgender individuals, HHS not only reverses existing regulations but also runs counter to nearly two decades of case law that say federal sex discrimination laws protect transgender communities.\textsuperscript{8}

Thank you for the opportunity to provide comments on the proposed rule. We believe the proposed changes would significantly harm people with disabilities and other marginalized groups. These proposed changes run counter to the very purpose of Section 1557. They are inconsistent with existing law and policy and the careful rationale for the existing rules developed during extensive notice and comment. In short, these changes are harmful, arbitrary, and capricious. We strongly urge HHS to withdraw this NRPM in its entirety and not to finalize these harmful proposed changes. If you have questions about our comments, please contact Alison Barkoff at abarkoff@cpr-ma.org

Sincerely,

Alison Barkoff
Director of Advocacy
Center for Public Representation

\textsuperscript{7} 45 C.F.R. § 92.206.