EXHIBIT 1

2019 Proposed Rule Cited Comments



August 13th, 2019

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

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

Dear Mr. Severino:

ACCESS thanks the Office for Civil Rights (OCR) at the U.S. Department of Health and Human Services (HHS) for the opportunity to comment on the notice of proposed rulemaking (NPRM) on Section 1557 of the Patient Protection and Affordable Care Act (ACA) ("Health Care Rights Law" or "Section 1557").

Grounded in a grassroots commitment to empowerment, ACCESS is the largest Arab American community nonprofit in the U.S., with a 48-year history of nonprofit of excellence. ACCESS was founded in by a group of immigrants and young Arab American volunteers for the purpose of supporting and advocating for the influx of immigrants to the Detroit area and their needs. Guided by our vision of a just and equitable society for all, with the full participation of Arab Americans, we empower communities in Southeast Michigan to improve their economic, social and cultural well-being. Our mission extends nationally through our highly esteemed institutions—The National Network for Arab American Communities (NNAAC), the Arab American National Museum (AANM) and the Center for Arab American Philanthropy (CAAP)—which are focused on making an impact through advocacy, the arts and philanthropy.

ACCESS provides direct services that span healthcare, social services, education programs, workforce training, and public benefits assistance, to over 70,000 clients a year. ACCESS delivers a wide array of culturally competent services to thousands of Arab Americans each year, while vastly expanding its reach. We work with an increasing number of African Americans, Latina/o Americans, and Asian Americans each year, along with many other communities of color and low-income communities. As an organization representing Arab Americans and diverse communities in the state of Michigan and across the country, we strongly oppose the NPRM's provisions which seek to eliminate and otherwise limit civil rights protections. Each day we work with diverse community members including immigrants, refugees who struggle to access health care they are legally entitled due to language, among other barriers.

Section 1557 prohibits discrimination on the basis of race, color, national origin, sex, age, and disability. As an organization that is committed to upholding the civil rights of all persons, we



strongly oppose the NPRM provisions which seek to eliminate and limit protections for individuals who are limited English proficient, LGBTQ+ persons, persons with disabilities and chronic conditions, and persons needing reproductive health services. Section 1557 addresses not only protections for each protected class covered, but the intersection of those protections. As such, an attack on the civil rights of one group in the NPRM is an attack on the civil rights of all.

The proposed rule would deeply impact the beneficiaries that we serve who are Arab American immigrants and refugees, among many other LEP populations. There are over 178,000 limited English proficiency (LEP) individuals in Southeast Michigan's tri-county area, the geographic region served by ACCESS, and the proposed rule would jeopardize the rights of this population, among others.

Our comments focus on the NPRM's language access provisions to ensure that LEP persons have the meaningful access required not only by Section 1557 but also by Title VI of the Civil Rights Act of 1964 (Title VI) and its implementing regulations. As such, we oppose eliminating the language access protections as proposed in the NPRM. We also oppose any other efforts to eliminate or roll back protections and provisions contained in the 2016 Nondiscrimination in Health Programs and Activities Final Rule (2016 Final Rule) as they apply to other protected classes.

Proposed § 92.101 Meaningful Access for Individuals with Limited English Proficiency

The proposed § 92.101 inappropriately switches the emphasis from "each individual with limited English proficiency" as provided in the 2016 Final Rule to the covered entity's program or activities. In Section 1557, Congress declared "an individual shall not" be subject to discrimination. Section 1557 regulations cannot offer less protection than the statute that authorizes such regulations. Therefore, the emphasis in the regulations must be on each individual and not programs. As such, this NPRM would weaken meaningful access, is counter to Congressional intent and the thorough administrative record supporting the 2016 Final Rule, and we oppose it. At ACCESS, we understand intimately that LEP individuals and families face specific barriers to accessing services and require additional, tailored support to meet their needs. Our programs, activities and materials are provided with particular accommodations to ensure they are accessible to LEP communities. We believe strongly that the emphasis should continue to be placed on individuals with limited English proficiency to guarantee that this population is not left behind.

Opposition to Current 1557 Provisions Proposed for Repeal or Reconsideration

Overall, we strongly disagree that the 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. In focusing most significantly on the costs to covered



entities and devoting minimal consideration to the costs to LEP individuals, OCR is not acting in accordance with the balancing principles identified by it in the 2003 HHS LEP Guidance which states "First we must ensure that federally assisted programs aimed at the American public do not leave some behind simply because they face challenges communicating in English."

a. Proposed Repeal of Nondiscrimination Notice

We oppose the repeal of the requirement that covered entities provide a notice of nondiscrimination that informs the public of their legal rights. The notice requirement is consistent with the long history of civil rights regulations requiring the posting of notice of rights.

OCR has provided no explanation for how individuals will know of their rights and how elimination of notices will not deny LEP individuals, LGBTQ+ persons, women and persons with disabilities meaningful access. 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, that they have the right to file a complaint, and how to file such a complaint. At ACCESS, this notice is crucial in allowing our community members to understand their rights and ultimately access and navigate the health care services they need. As a nonprofit organization with limited resources and capacity, we are also concerned about the added burden and cost to our organization if we are put in a position to allocate additional resources into informing people of their rights due to the absence of such notices.

OCR incorrectly asserts that the nondiscrimination notice is redundant of existing civil rights notices under other statutes. Rather, the notice recognizes the fact that individuals may face multiple forms of discrimination and in fact eliminates duplication by consolidating the underlying statutes' notice requirements into one.

b. Proposed Repeal of In-Language Taglines

We strongly oppose the repeal of the requirement for covered entities to provide in-language taglines informing recipients of the availability of language assistance on significant documents because, combined with the elimination of the nondiscrimination notice, the repeal threatens the civil rights of LEP persons. The inclusion of taglines is well-supported by long-standing federal and state regulations, guidance and practice. The use of taglines is a cost-effective approach to ensuring that covered entities are not overly burdened while maintaining access for LEP individuals.

While taglines do not completely break the barriers faced by LEP individuals, we have found that they are useful in providing our communities with some assurance that there are resources available to support them. In the absence of fully 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." As such, we oppose their elimination.

The Regulatory Impact Analysis is Flawed and Ignores Costs to LEP Individuals

a. The Regulatory Impact Analysis (RIA) is Insufficient and Fails to Justify the Proposals
The NPRM provides an RIA that is insufficient to justify the extensive scope of the proposed
changes to language access, and fails to identify and quantify costs to protected individuals.
OCR centered the elimination of the notice and taglines on estimates based on voluntary
interpretations by covered entities, but did not consider whether alternatives, such as further
clarification about the requirements, was warranted. OCR failed to consider alternatives to a
complete repeal of notices and taglines that could have appropriately balanced the need to
inform individuals of their rights while recognizing there may be a difference in intentions
behind the 2016 Final Rule and how entities have interpreted it.

Similarly, the majority of the costs are associated with the provision of a single type of document -- the Explanation of Benefits (EOB). OCR did not consider alternatives as to how it would consider enforcement and interpretation of the "significant document" standard with respect to the provision of multiple EOBs sent during a coverage year.

OCR states it has received little evidence that more beneficiaries are seeking language assistance and uses this claim as a justification to remove the notice and taglines. This claim, which relies on reports from health plans, is insufficient to justify their repeal. The regulation has been in effect for three years in which OCR, by its own admission, has had limited resources to conduct public outreach. Notices and taglines were also selected as a compromise position, to avoid requiring covered entities to translate large numbers of documents. LEP persons are also uniquely at risk of facing barriers to knowing and asserting their rights. Lack of uptake of services raises questions about the extent to which the public knows its rights and what covered entities are doing to communicate those rights, as opposed to justifying elimination of notices and taglines.

Our communities already face a number of barriers in knowledge access around their civil rights protections due to a lack of outreach, education and other types of more direct support to supplement nondiscrimination notices and in-language taglines. As a community that is increasingly targeted on the basis of background, ethnicity and language, civil rights protections are also a topic of concern and stigma. These changes would further burden organizations like ACCESS, along with the communities served, and ultimately put vulnerable populations at risk. We believe more resources, rather than less, must be allocated in this area to ensure that LEP individuals are knowledgeable of their rights.



b. Language Access Requirements in the 2016 Final Rule Are Justified by Need OCR has provided no tangible analysis of the costs and burdens of repealing the notice and tagline requirement, and provides only acknowledgment that repeal "may impose costs, such as decreasing access to, and utilization of, health care for non-English speakers by reducing their awareness of available translation services." OCR labels the impact as "negligible" while providing no evidentiary basis. The costs are not only reduced awareness of language services by LEP persons, but also by the general public about their rights as protected by 155.

Discrimination on the basis of national origin, which encompasses discrimination on the basis of language, creates inequitable access to health care. Language access in health care is just as critical now as when the Civil Rights Act was originally passed in 1964. Over twenty-five million individuals in the United States are LEP. An estimated 19 million LEP adults are insured. Language assistance is necessary for LEP persons to access federally funded programs and activities in the healthcare system. Without meaningful access, the estimated 25 million individuals who are LEP would be excluded from programs and services they are legally entitled to, including the over 178,000 individuals here in the metro Detroit area and the thousands served by ACCESS each year. We urge HHS to withdraw and not finalize this rule.

Thank you for the opportunity to comment on the nondiscrimination NPRM.

Sincerely,

Farah Erzouki, MPH

Forch Ezzouki

Public Health Programs Manager ACCESS Community Health and Research Center



August 13, 2019

U.S. Department of Health and Human Services Office for Civil Rights Attention: Section 1557 NPRM, RIN 0945-AA11 Hubert H. Humphrey Building, Room 509F 200 Independence Avenue SW Washington, DC 20201

Submitted electronically

Re: Comment on Proposed Rule Regarding Section 1557, Health Care Rights Law

The ACLU of Northern California, the ACLU of Southern California, and the ACLU of San Diego and Imperial Counties (collectively "ACLU of California") submit these comments on the proposed rule published at 84 Fed. Reg. 27,846 (June 14, 2019), RIN 0945-AA11, with the title "Nondiscrimination in Health and Health Education Programs or Activities" (the "Proposed Rule").

The ACLU of California is a collaboration of the three California-based ACLU affiliates with more than 270,000 members and supporters, working to protect and advance the civil rights and civil liberties of all Californians. The ACLU of California has a long history of working to advance access to quality healthcare for all individuals and has specific experience and expertise in preserving and enhancing access to care for lesbian, gay, bisexual, transgender, and queer ("LGBTQ") individuals and for people in need of reproductive health care services. The ACLU of California is thus particularly well-positioned to comment on the Proposed Rule and the serious concerns it raises about access to health care.

The rule currently in place implementing Section 1557, titled "Nondiscrimination in Health Programs and Activities" (the "Current Rule"), was developed after years of review and consideration of comments from a variety of stakeholders. The Current Rule meets a critical need and fulfills Congress's intent to provide "equal access to health services and health insurance that all individuals should have, regardless of their race, color, national origin, age, or disability." 81 Fed. Reg. 31,459. Discrimination in the health care context leads to lasting harms to people's health and wellbeing, and the Department of Health and Human Services (the "Department" or "HHS") made detailed factual findings to that effect in support of the Current Rule: People subject to discrimination postpone or fail to obtain health services and are denied necessary care; such discrimination exacerbates health disparities in underserved communities.

The Proposed Rule, however, is yet another attempt by the Trump Administration and HHS to undermine access to health care for the most vulnerable individuals and communities, while emboldening discriminatory and dangerous denials of care. The Proposed Rule's explicit reductions in the scope of antidiscrimination protections, as well as the implicit invitation for health care providers to undermine access to care, completely disregard the potential harms to individuals trying to access health care and coverage. This approach is contrary to the statutory language of Section 1557, and is a reversal of the reasoned policy decisions underlying the Current Rule. Further, it will fail to accomplish its stated goal to *decrease* confusion, instead *increasing* the burdens and costs of compliance.

For these reasons, as well as the ones that follow, the ACLU of California recommends that the Department decline to finalize the Proposed Rule in its entirety.

I. THE PROPOSED RULE SHOULD NOT ROLL BACK AFFIRMATIVE ANTIDISCRIMINATION PROTECTIONS.

A. HHS Should Maintain the Existing Definition of Discrimination on the Basis of Sex and Protections Against Such Discrimination.

In promulgating the Current Rule, the Department recognized the importance of affirmative regulatory protections—specifically against all enumerated forms of sex discrimination. The Current Rule defines discrimination based on sex to include discrimination on the basis of pregnancy, false pregnancy, termination of pregnancy, or recovery therefrom, childbirth or related medical conditions, sex stereotyping, and gender identity. 45 CFR 92.4. The Proposed Rule eliminates this key provision that clarifies what discrimination on the basis of sex encompasses, and removes explanatory examples of prohibited activity. The Proposed Rule also amends regulations—and incorporates an abortion exemption—that are unrelated to Section 1557. These changes are without justification and will directly harm patients seeking care.

1. The proposed amendments abandon LGBTQ individuals and people seeking reproductive health care, who depend on HHS to protect their statutory rights.

Section 1557 and the Current Rule are intended to protect people from the pervasive problem of sex-based discrimination in the health care context. LGBTQ patients, as well as people who seek or have obtained reproductive health services, face discrimination based on sex in accessing health care. This discrimination can range from providers using harassing or abusive language to completely refusing necessary medical care. Sex-based exclusions from health care coverage can also make essential medical care unaffordable. For example, some transgender and non-binary individuals are subject to discriminatory categorical exclusions for health care related to gender transition that put necessary health care out of financial reach. By eliminating the definition of discrimination on the basis of sex, as well as stripping protections against discrimination based on gender identity and sexual orientation from other unrelated HHS regulations, the Proposed Rule will invite such discrimination against LGBTQ individuals and people seeking reproductive health care.

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Though the federal government's own Office of Disease Prevention and Health Promotion recognizes that lesbian, gay, bisexual, and transgender ("LGBT") people face disproportionate health disparities linked to societal stigma, discrimination, and denial of their civil and human rights¹, HHS fails to even consider the impact that the Proposed Rule would have on individuals who are protected under the Current Rule.

According to a study published by the Williams Institute in March 2019, approximately 1,615,000 adults in California openly identify as LGBT, accounting for 5.3 percent of California's adult population; and of those, 218,400 adults in California openly identify as transgender, accounting for 0.76 percent of California's population. LGBT people in California are more likely to be unemployed, food insecure, and living below the federal poverty line than their non-LGBT counterparts, suggesting an increased need for affordable and quality health care.

The Department must prioritize the impact that inviting discrimination against patients will have on public health, particularly the harms to transgender and non-binary individuals, as well as people who need or have obtained pregnancy-related health services, all of whom would no longer have explicit regulatory protections against sex discrimination if the Proposed Rule is finalized.

2. The proposed amendments do not provide clarity, but only create more confusion.

The Department contends that the Proposed Rule is needed to reduce confusion and to clarify the scope of Section 1557. But should the Department delete the definitional provisions, it would actually *cause* confusion and embolden health care and insurance providers to discriminate. The Department's proposal does nothing to clarify what constitutes prohibited sex discrimination under Section 1557, as eliminating the definition does not mean that discrimination on the presently enumerated bases is suddenly permitted. Instead, eliminating the definition invites discrimination and undermines uniformity among providers—to the detriment of covered entities and patients alike.

Because discrimination based on sex would still be prohibited, discrimination based gender identity would remain unlawful under Section 1557 as well. In Section 1557, Congress directed HHS to apply existing civil rights law and regulations to healthcare and the ACA

¹ Lesbian, Gay, Bisexual, and Transgender Health, (last accessed Aug. 8, 2019), available at: https://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health.

² Adult LGBT Population in the United States, UCLA School of Law Williams Institute, March 2019, https://williamsinstitute.law.ucla.edu/wp-content/uploads/How-Many-Adults-Identify-as-Transgender-in-the-United-States.pdf.

³ See *id*.

exchanges, including Title IX of the Education Amendments Act of 1972 prohibiting discrimination on the basis of sex in federally funded educational programs and activities. Courts have consistently held that Title IX's prohibition on sex discrimination protects individuals from discrimination based on gender nonconformity. See EEOC v. R.G. &. G.R. Harris Funeral Homes, Inc., 884 F.3d 560, 572 (6th Cir. 2018), cert. granted in part, 139 S. Ct. 1599 (2019); Whitaker ex rel. Whitaker v. Kenosha Unified Sch. Dist. No. 1 Bd. of Educ., 858 F.3d 1034, 1046–54 (7th Cir. 2017); Glenn v. Brumby, 663 F.3d 1312, 1316 (11th Cir. 2011); Schwenk v. Hartford, 204 F.3d 1187, 1201 (9th Cir. 2000); Rosa v. Park W. Bank & Tr. Co., 214 F.3d 213, 215–16 (1st Cir. 2000). District courts across the country have also recognized that discrimination against transgender individuals because their gender identity diverges from their sex assigned at birth violates the plain text of Section 1557. See Tovar v. Essentia Health, 342 F. Supp. 3d 947, 953 (D. Minn. 2018); Flack v. Wis. Dep't of Health Servs., 328 F. Supp. 3d 931, 951 (W.D. Wis. 2018); Prescott v. Rady Children's Hosp.-San Diego, 265 F. Supp. 3d 1090, 1098–1100 (S.D. Cal. 2017). Given the extensive legal precedent, the Department cannot simply assert by regulation that covered entities will not be liable for gender identity discrimination claims where such discrimination is prohibited by the statutory text.

Further, while the preamble to the Proposed Rule attempts at inordinate length to justify the elimination of gender identity as an identified form of sex discrimination, it does not explain why the other definitional provisions are eliminated as well. Removing the definition of sex discrimination cannot change the underlying legal precedent that the current definition was based on and that still prohibits discrimination on the enumerated bases, including discrimination based on gender identity and pregnancy.

For example, the following California laws prohibit discrimination based on gender identity, gender expression, pregnancy, childbirth, and related medical conditions, and have long supported the argument that discrimination on the basis of sex encompasses such categories:

• The California Fair Employment and Housing Act (FEHA) expressly prohibits discrimination by employers, labor organizations, and apprenticeship training programs on the basis on sex, which is defined to include pregnancy, childbirth, and related medical conditions, and on the basis of gender identity and gender expression as independent protected categories. Cal. Gov't Code § 12940. FEHA provides specifically that, while employers may impose gender-based dress codes, an employee must be permitted to appear or dress in a manner consistent with their gender identity. Cal Gov't Code § 12949. FEHA also prohibits gender identity discrimination related to renting, buying, and selling a house, which extends to public and private land use and real estate listings. Cal. Gov't Code §§ 12955(l), (j).

Even prior to the addition of gender identity as an express category in 2011, California recognized that statutorily prohibited discrimination on the basis of "sex" encompassed gender identity. See, e.g., In the Matter of the Accusation of the Dep't of Fair Employment & Hous. (Feb. 1, 2006) FEHC Dec. No. 06-01 (finding that the challenged policy impermissibly promoted the sex stereotype that men should not wear "feminine attire" and that anti-transgender discrimination was prohibited as sex discrimination under the Unruh Act).

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- The California Unruh Civil Rights Act (Unruh Act) prohibits sex discrimination in public accommodations and defines "sex" to include gender identity, gender expression, pregnancy, childbirth, and related medical conditions. Cal Civ. Code § 51. The Unruh Act has been found to apply to physicians' offices and hospitals that serve the public. See, e.g., North Coast Women's Care Med. Group v. San Diego County Sup. Ct., 44 Cal.4th 1145 (2008) (medical group providing services to the public is a "business establishment" under the Unruh Act).
- The California Education Code prohibits discrimination on the basis of gender and prohibits instruction or school-sponsored activities that "promote[] a discriminatory bias". Cal. Educ. Code §§ 220; 51500. "Gender" under the California Education Code is defined to include gender identity and gender expression. Cal. Educ. Code § 210.7.
- The California Insurance Gender Nondiscrimination Act prohibits health plans from discriminating against individuals based on sex and defines "sex" to include gender identity and gender expression. Cal. Health & Saf. Code, § 1365.5.

To the extent there is variance among California and federal courts as to what constitutes discrimination based on sex, the Current Rule provides crucial uniformity.

3. HHS should not import an abortion exemption into its definition of sex discrimination.

The Proposed Rule would unnecessarily incorporate the abortion exemption from Title IX into regulations implementing Section 1557. Incorporating the abortion exemption violates the text and purpose of Section 1557, which prohibits discrimination "on the *ground[s]* prohibited under" the referenced civil rights statutes, not the attendant exemptions contained in those statutes. 42 U.S.C. § 18116 (emphasis added). Congress has already spoken clearly as to the restrictions it intended to place on abortion care and coverage, through both the ACA itself, *see* 42 U.S.C. § 18023(b)(1)(A), (b)(4), as well as the Weldon, Church, and Coats Amendments. Abortion care is health care related to pregnancy, and targeting it for exclusion undermines and stigmatizes access to care that is a constitutionally protected right and a necessity for millions of Americans.

* * *

Taken as a whole, the Proposed Rule strips explicit regulatory protections for LGBTQ individuals and for people who require reproductive health care, indicating that the underlying purpose for the amendments is to target transgender and non-binary individuals, as well as other people who face sex-based discrimination in accessing health care and insurance coverage. That is neither consistent with the text of the statute, nor the appropriate mission of the Department. The Proposed Rule is also untimely, as the U.S. Supreme Court plans to hear argument in October in three cases addressing whether sex discrimination encompasses discrimination based on sexual orientation, gender identity, and discrimination against transgender individuals due to

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sex stereotyping under Title VII. *Altitude Exp., Inc. v. Zarda*, 139 S. Ct. 1599 (2019); *Bostock v. Clayton Cty., Ga.*, 139 S. Ct. 1599 (2019); *R.G. & G.R. Harris Funeral Homes, Inc. v. EEOC*, 139 S. Ct. 1599 (2019). Because Title IX generally adopts the standards for discrimination under Title VII, the Department will need to address the practical implications of any decision by the Court through a renewed comment process. Accordingly, the Department should abandon the Proposed Rule and instead leave in place the existing rule that discrimination based on gender identity is a form of sex discrimination, as is discrimination based on pregnancy, false pregnancy, termination of pregnancy, or recovery therefrom, childbirth or related medical conditions, and sex stereotyping.

B. HHS Should Not Weaken Protections for People with Disabilities.

Historically, people with disabilities in the United States have been unable to access the health care they need because of discrimination by the health insurance industry. Prior to the ACA, people with disabilities were commonly denied or terminated from health coverage, faced annual and lifetime benefit limits, and could not find affordable coverage. Access to adequate health care at affordable rates is central to the ability of disabled people to participate fully in society.

The Department proposes to eliminate Section 92.207 of the Current Rule in its entirety, which would undermine the right of people with disabilities to challenge discriminatory benefit design. Under the Current Rule, for example, plans that cover bariatric surgery in adults but exclude such coverage for adults with particular developmental disabilities, place most or all drugs that treat a specific condition on the highest cost tiers, or exclude bone marrow transplants regardless of medical necessity, constitute disability discrimination in violation of Section 1577. The Department claims that the provision is redundant or may be confusing in relation to the Department's preexisting regulations. But the Current Rule is needed precisely because existing laws were insufficient to dismantle barriers to adequate health insurance for people with disabilities. The deletion thus contravenes Section 1557's plain language.

The application of antidiscrimination principles to health insurers and to benefit design is essential to the needs and rights of disabled people. The Proposed Rule does not apply those principles and should not be adopted.

C. HHS should not weaken protections for individuals with Limited English Proficiency.

The Department should not eliminate the language access protections as described by the Proposed Rule. In California, there are 6,766,073 people with limited English proficiency⁴ ("LEP"), 39.5 percent of Californians speak a language other than English at home, and one in

⁴ Limited English Proficient (LEP), An Inter-Agency Website, *Total Persons 5 Years and Over Who Speak a Language Other Than English at Home and Speak English Less Than "Very Well"*, (last visited: August 12, 2019), available at: https://www.lep.gov/maps/2015/national/US_state_LEP_count.ACS_5yr.2015.pdf.

five Californians has a level of English proficiency that suggests that they would benefit from language assistance when accessing the health care system.⁵ These Californians should all have meaningful access to health care and coverage. Language assistance is necessary to ensure that LEP persons are guaranteed such access, and is a critical protection to combat discrimination on the basis of national origin, which encompasses discrimination on the basis of language.

The Proposed Rule would eliminate significant protections for LEP persons by removing the requirement that covered entities provide notices of legal rights and in-language taglines on significant publications. The taglines are cost-effective ways to maintain access for LEP individuals without translating entire documents. The Department ignores the impact on LEP individuals should this requirement be eliminated, relying solely on reports from health plans, with no public outreach to determine the impact of the taglines or to explore alternatives. Likewise, the Department should not eliminate references to language access plans, which are a useful tool for covered entities to fully plan how to meet the needs of LEP patients and consumers. Such plans also support covered entities' own compliance efforts, benefiting both LEP individuals and covered entities alike.

LEP individuals face unique risks and barriers to knowing and asserting their rights in the health care context. In California, studies have found that LEP individuals are less likely to have a usual source of health care, less likely to have had a mammogram in the last two years, and have lower rates of crucial diagnostic blood tests. Overall, language barriers reduce patient access to health care, even among patients with health insurance coverage through Medicare. Language barriers in health care result in life and death consequences for LEP patients; they face difficulties in communicating directly with providers about their symptoms and needs, and prescription instructions are often not translated properly and can result in misuse of prescribed medicine. LEP patients need more and better access to translation and interpretation services, not less. The proposed rule puts the health and well-being of LEP patients in jeopardy by scaling back crucial language access protections. The proposed elimination of protections to aid communication with LEP individuals—both while they are accessing services and so that they know their rights—should be abandoned.

⁵ Chen, Alice Hm, *Language Barriers in Health Care Settings: An Annotated Bibliography of the Research Literature*, 1, The California Endowment (August 2003) available at: https://ncihc.memberclicks.net/assets/documents/cal.endow.bibliography.pdf.

⁶ Once, Ninez A., Ku, Leighton, Cunningham, William E., Brown, Richard E., *Language Barriers to Health Care Access Among Medicare Beneficiaries*, Inquiry 43: 66–76 (Spring 2006), available at: https://publichealth.gwu.edu/departments/healthpolicy/DHP_Publications/pub_uploads/dhpPublication_3B0D8691-5056-9D20-3D5363F46853C7A6.pdf.

⁷ Id.

⁸ Guzik, Hannah, *Language Barriers in California Health Care*, The California Health Report (May 27, 2014), available at: https://www.calhealthreport.org/2014/05/27/language-barriers-in-california-health-care/.

II. THE DEPARTMENT SHOULD NOT LIMIT THE BROAD INTENDED IMPACT OF SECTION 1557.

The Proposed Rule includes several provisions that would so limit Section 1557's application as to render its protections a nullity for the very people Congress sought to protect. The proposal inappropriately limits the statute's reach in several respects and, as such, the Department should decline to finalize the Proposed Rule, leaving in place the Current Rule.

A. HHS Should Not Import a Religious Exemption into Section 1557.

The Proposed Rule wrongly would allow religiously affiliated healthcare providers to discriminate based on sex and to refuse access to necessary medical care, by importing Title IX's expansive religious exemptions into Section 1557. Religiously affiliated healthcare providers make up a significant percentage of the healthcare facilities in the United States. One in six patients is now treated in a Catholic facility each year, and religious hospitals are also gradually becoming the *only* health care option in many regions.

In California, as in many parts of the country, the size and scope of Catholic hospitals has been increasing in recent years. At present, there are 37 general acute care hospitals throughout the state that follow Catholic doctrine. In the Northern California communities of Red Bluff and Redding, Catholic hospitals are the only option for patients in the region.

The largest hospital provider in California is Dignity Health, a Catholic-affiliated health system. Dignity Health requires its hospitals and other facilities to follow the Ethical and Religious Directives for Catholic Healthcare Services or its Statement of Common Values. Both documents are non-medical and restrict physicians from practicing medicine in alignment with their training and with patients' autonomy.

Dignity Health is in the process of merging with Catholic Health Initiatives to create CommonSpirit Health. This new entity is projected to be responsible for caring for one in six patients in this country. Aside from the sheer numbers of patients who rely on these institutions for care, mergers of this type increasingly give Catholic entities outsize influence and corporate power in the health care market. A worst-case scenario would be that these entities, which push non-medical restrictions on their patients and improperly interfere in the patient-provider relationship, set the industry standard in health care.

The proposed religious exemption violates the text and purpose of Section 1557, as well as the constitutional commitment to the separation of church and state. The statute prohibits discrimination "on the *ground[s]* prohibited under" the referenced civil rights statutes, 42 U.S.C. § 18116 (emphasis added), but does not incorporate the attendant exemptions contained in those statutes—many of which are wholly inapposite to the health care context. The Department should not reverse course by incorporating the exemption, having initially rejected invitations to do so. Further, the First Amendment forbids government action favoring religion to the point of

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forcing third parties to bear the costs of those beliefs. *See Estate of Thornton v. Caldor, Inc.*, 472 U.S. 703, 708–10 (1985). The Proposed Rule's exemption flies in the face of the careful balance courts have struck between civil rights and religious liberty, running afoul of the Establishment Clause.

Permitting a blanket religious exemption to Section 1557's nondiscrimination mandate threatens access to critical care for countless patients, especially transgender patients and patients seeking reproductive health services. The Proposed Rule altogether fails to consider the harmful consequences of importing a broad religious exemption into the health care context.

The ACLU of California has collected stories of denials of healthcare based on religious directives as part of our All Care Everywhere campaign. The stories of Oliver, Evan, Tyler, Rebecca, and Sarah below demonstrate that people are turned away or denied services for medically necessarily, life-saving care, running counter to medical ethics and training.

Oliver Knight lives in Humboldt County, California where Catholic hospitals dominate. Oliver was prepped and ready for gender-affirming surgery at St. Joseph Hospital in Eureka when his doctor informed him that this common procedure was being refused by the hospital pursuant to the hospital's religious policies. Minutes later, Oliver was asked to leave the hospital. He still had booties on his feet as the nurse escorted him outside. Oliver felt humiliated as he sat on the curb waiting for his roommate to pick him up. In March 2019, The ACLU Foundation of Northern California, ACLU Foundation of Southern California, and the law firm Rukin Hyland & Riggin filed a lawsuit on behalf of Oliver Knight.

Evan Minton was scheduled to receive a hysterectomy at Mercy San Juan Medical Center, a hospital in the Dignity Health system, near Sacramento. Two days prior to the appointment, a nurse called to discuss the surgery and Evan mentioned that he is transgender. The next day, the hospital canceled the procedure. The delay put Evan's other scheduled treatments in flux until he was eventually able to schedule the surgery at another hospital. Evan's doctor said that she routinely performs hysterectomies at Mercy San Juan and had never before been prevented from performing the surgery. In April 2017, the ACLU Foundation of Northern California, ACLU Foundation of Southern California, and the law firm Covington & Burling LLP filed a lawsuit on behalf of Evan Minton.

Rebecca Chamorro, a patient at Mercy Medical Center Redding, decided with her obstetrician that she would receive a postpartum tubal ligation immediately following her scheduled C-section. Her obstetrician sought authorization from Mercy Medical Center, a Dignity Health hospital, to perform the tubal ligation, which would only take a few minutes and required no additional resources from the hospital. Mercy Medical Center refused her obstetrician's request to perform the procedure, citing religious directives that deem sterilization procedures as "intrinsically evil." In December 2015, the ACLU Foundation of Northern California, ACLU Foundation of Southern California, and law firm Covington & Burling LLP filed a lawsuit on behalf of Rebecca Chamorro.

Sarah, a patient at Mercy Medical Center Redding, sought authorization with her obstetrician for the same procedure as Rebecca Chamorro, a postpartum tubal ligation immediately following a scheduled C-section. Mercy Medical Center was the only hospital within 150 miles of Sarah's home and her only available, affordable option for the C-section and tubal ligation. Sarah was devastated when the hospital refused her obstetrician's request to perform the procedure.

When Tyler decided to pursue gender-affirming surgery, St. Joseph's Santa Rosa Memorial Hospital near Tyler's home and community was the natural hospital choice. After her doctor had trouble scheduling the surgery, Tyler drove to the hospital to schedule the surgery in person. The hospital staff misgendered Tyler and denied her gender-affirming surgery, citing their religious directives. She felt humiliated and dehumanized.

Allowing a religious exemption to section 1557's nondiscrimination mandate would further threaten patients' access to the critical health care they need.

B. HHS Should Not Narrow the Scope of Covered Entities.

The Proposed Rule would further undercut Section 1557 by limiting the entities covered by the provision. Limiting the application of Section 1557's protections would sanction discriminatory denials of coverage by entities that are presently covered by Section 1557, causing confusion and serious harm to those unable to access care. Additionally, the Proposed Rule displays no awareness of the potential harm to individuals denied coverage of and access to health care due to the proposed limitations on Section 1557's application.

Excluding health insurance from Section 1557's nondiscrimination mandate as distinct from "health program or activity" is contrary to the text of the statute and the broader antidiscrimination purpose of the law. The false distinction is exacerbated by the Proposed Rule's new limitation on the application of Section 1557 in cases where the entity is not "principally engaged in the provision of health care." In such cases, under the proposal, Section 1557 would apply only to the specific operations of an entity that receive federal financial assistance—whereas Section 1557 covers *all* operations of entities principally engaged in health care that receive federal financial assistance. This distinction, too, is contrary to the text of the statute, which prohibits discrimination under "any health program or activity, *any part of which* is receiving Federal financial assistance." 42 U.S.C. § 18116 (emphasis added).

C. HHS Should Maintain Existing Remedies Available for Section 1557 Claims.

The Current Rule adopts a uniform standard, applicable to all grounds covered by Section 1557, and incorporates enforcement mechanisms that exist under any of the civil rights laws referenced by Section 1557. This includes a private right of action for disparate-impact claims and the availability of compensatory damages for all claims under Section 1557. In removing these provisions, the proposed rule creates a scheme in which people are denied certain legal remedies because of the type of discrimination they experience. Such a change also privileges

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purported business interests in relieving regulatory burdens over the interests of the public and of individuals seeking health care. However, by removing the certainty of the Current Rule, covered entities and protected individuals alike would be uncertain as to the law's requirements and protections, instead leaving them to look to four other separate civil rights laws and various agencies' implementing regulations for clues.

The Proposed Rule's silence regarding the availability of a private right of action is at worst contrary to the rights-expanding aims of the statute and, at best, purposeless. Parties asserting private rights of action pursuant to Section 1557 have significantly expanded access to health care and combatted discriminatory health care policies, and will continue to do so, regardless of regulatory language explicitly affirming that such a right exists.

The Department should also not eliminate the Current Rule's provision for disparate-impact claims, which promotes better compliance with Section 1557's nondiscrimination provisions. The disparate-impact mechanism encourages health care providers to identify disparities and to adopt solutions that make a crucial difference in eliminating those disparities for individuals and improving public health.

These enforcement mechanisms are particularly important for people of color. Addressing racial disparities in health care is a matter of life and death. Such disparities are found across a range of illnesses and health care services, even when accounting for socioeconomic factors. Disparities in health care also have historic roots. As in other sectors of society, segregated health care was once sanctioned by law, and government-sanctioned discrimination continues to have a systemic impact on access to quality health care. At the same time, research suggests that many racial and ethnic health disparities could be reduced or even eliminated if identified and addressed. A disparate-impact private right of action is a crucial enforcement mechanism to confront and redress discrimination.

The Department's proposal would instead make enforcement more difficult, and would increase confusion as to the scope of Section 1557's protections. The Department should accordingly continue to affirm existing enforcement mechanisms, including the private right of action for disparate-impact claims.

D. The Department Should Not Eliminate Grievance Procedures and Notice Requirements.

The Proposed Rule would unnecessarily eliminate the specific grievance procedures established under Section 1557, which would leave covered entities and impacted individuals without cohesive, uniform procedures for investigating grievances. Further, the Department should not eliminate the explicit requirement that such procedures "incorporate appropriate due process standards," which provides that the procedures in place are sufficient to address claims of discrimination promptly and equitably. 45 CFR 92.7. Likewise, the Department should not eliminate the requirement that covered entities provide notice to the public that they do not discriminate, as the current procedure is crucial to ensure that individuals are aware of the safeguards in place and of the steps they can take to effectuate the protections under Section

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1557. 45 CFR 92.8. The costs associated with the notice requirement are well worth the benefit of ensuring that protected individuals receive adequate notice of their rights.

III. THE PROPOSED RULE VIOLATES SECTION 1554 OF THE ACA.

The Proposed Rule is additionally contrary to law because it violates another provision of the ACA: Section 1554. This provision limits the Department's rulemaking authority, prohibiting HHS from promulgating regulations that create any unreasonable barriers to the ability of individuals to obtain appropriate medical care, impede timely access to health care services, violate the ethical standards of health care professionals, or limit the availability of health care treatment for the full duration of a patient's medical needs—among other restrictions. 42 U.S.C. § 18114. For all the reasons outlined in this comment, the Proposed Rule represents a direct violation of Congress's command and should be entirely abandoned.

* * *

For all these reasons, the Department should withdraw the Proposed Rule.

* * *

Sincerely,

Aditi Fruitwala

ACLU Foundation of Southern California

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Amanda Goad

ACLU Foundation of Southern California

Elizabeth Gill

ACLU Foundation of Northern California

Melissa Deleon ACLU Foundation of San Diego and Imperial Counties August 13, 2019

U.S. Department of Health and Human Services Office for Civil Rights Attention: Section 1557 NPRM, RIN 0945-AA11 Hubert H. Humphrey Building, Room 509F 200 Independence Avenue SW Washington, DC 20201

Submitted electronically

Re: Comment on Proposed Rule Regarding Section 1557, Health Care Rights Law

The ACLU of Hawai'i submits these comments on the proposed rule published at 84 Fed. Reg. 27,846 (June 14, 2019), RIN 0945-AA11, with the title "Nondiscrimination in Health and Health Education Programs or Activities" (the "Proposed Rule").

The mission of the ACLU of Hawai'i is to protect the fundamental freedoms enshrined in the U.S. and State Constitutions. The ACLU of Hawai'i fulfills this through legislative, litigation, and public education programs statewide. The ACLU of Hawai'i is a non-partisan and private non-profit organization that provides its services at no cost to the public and does not accept government funds. The ACLU of Hawai'i has been serving Hawai'i for over 50 years.

The rule currently in place implementing Section 1557, titled "Nondiscrimination in Health Programs and Activities" (the "Current Rule"), was developed after years of review and consideration of comments from a variety of stakeholders. The Current Rule meets a critical need and fulfills Congress's intent to provide "equal access to health services and health insurance that all individuals should have, regardless of their race, color, national origin, age, or disability." 81 Fed. Reg. 31,459. Discrimination in the health care context leads to lasting harms to people's health and wellbeing, and the Department made detailed factual findings to that effect in support of the Current Rule: People subject to discrimination postpone or fail to obtain health services and are denied necessary care; such discrimination exacerbates health disparities in underserved communities.

The Proposed Rule, however, is yet another attempt by the Trump Administration and the Department of Health and Human Services (the "Department" or "HHS") to undermine access to health care for the most vulnerable individuals and communities, while emboldening discriminatory and dangerous denials of care. The Proposed Rule's explicit reductions in the scope of antidiscrimination protections, as well as the implicit invitation for health care providers to undermine access to care, completely disregard the potential harms to individuals trying to access health care and coverage. This approach is contrary to the statutory language of Section 1557, and is a reversal of the reasoned policy decisions of the Current Rule. Further, it will fail to accomplish its stated goal to *decrease* confusion, instead *increasing* the burdens and costs of compliance.

For these reasons, as well as the ones that follow, ACLU of Hawai'i recommends that the Department decline to finalize the Proposed Rule in its entirety.

I. THE PROPOSED RULE SHOULD NOT ROLL BACK AFFIRMATIVE ANTIDISCRIMINATION PROTECTIONS

A. HHS Should Maintain the Existing Definition of Discrimination on the Basis of Sex and Protections Against Such Discrimination.

In promulgating the Current Rule, the Department recognized the importance of affirmative regulatory protections—specifically for all enumerated forms of sex discrimination. The Current Rule defines discrimination based on sex to include discrimination on the basis of pregnancy, false pregnancy, termination of pregnancy, or recovery therefrom, childbirth or related medical conditions, sex stereotyping, and gender identity. 45 CFR 92.4. The Proposed Rule eliminates this key provision that clarifies what discrimination on the basis of sex encompasses, and removes explanatory examples of prohibited activity. The Proposed Rule also amends regulations—and incorporates an abortion exemption—that are unrelated to Section 1557. These changes are without justification and will directly harm patients seeking care.

1. The proposed amendments abandon LGBT individuals and people seeking reproductive health care, who depend on HHS to protect their statutory rights.

Section 1557 and the Current Rule are intended to protect people from the pervasive problem of sex-based discrimination in the health care context. Lesbian, gay, bisexual, and transgender ("LGBT") patients, as well as people who seek or have obtained reproductive health services, face discrimination based on sex in accessing health care. This discrimination can range from providers using harassing or abusive language to completely refusing necessary medical care. Sex-based exclusions from health care coverage can also make essential medical care unaffordable. For example, some transgender and non-binary individuals are subject to discriminatory categorical exclusions for health care related to gender transition that put necessary health care out of financial reach. By eliminating the definition of discrimination on the basis of sex, as well as stripping protections against discrimination based on gender identity and sexual orientation from other unrelated HHS regulations, the Proposed Rule will invite such discrimination against LGBT individuals and people seeking reproductive health care.

The Department fails to even consider the impact that the Proposed Rule would have on individuals who are protected under the Current Rule. Hawai'i has the highest percentage in the nation of its adult population identifying as transgender; Hawai'i has historically embraced and celebrated gender and sexual diversity. In pre-colonial Hawai'i, māhū (who today may be considered transgender) were respected and played an important spiritual role in customary and traditional practices. The Department must prioritize the impact that inviting discrimination against patients will have on public health, particularly the harms to transgender and non-binary

individuals, as well as people who need or have obtained pregnancy-related health services, all of whom would no longer have explicit regulatory protections against sex discrimination if the Proposed Rule is finalized.

2. The proposed amendments do not provide clarity, but only create more confusion.

The Department contends that the Proposed Rule is needed to reduce confusion and to clarify the scope of Section 1557. But should the Department delete the definitional provisions, it would actually *cause* confusion and embolden health care and insurance providers to discriminate. The Department's proposal does nothing to clarify what constitutes prohibited sex discrimination under Section 1557, as eliminating the definition does not mean that discrimination on the presently enumerated bases is suddenly permitted. Instead, eliminating the definition invites discrimination and undermines uniformity among providers—to the detriment of covered entities and patients alike.

Because discrimination based on sex would still be prohibited, discrimination based on gender identity would remain unlawful under Section 1557 as well. Courts have consistently held that Title IX's prohibition on sex discrimination protects individuals from discrimination based on gender nonconformity. See EEOC v. R.G. &. G.R. Harris Funeral Homes, Inc., 884 F.3d 560, 572 (6th Cir. 2018), cert. granted in part, 139 S. Ct. 1599 (2019); Whitaker ex rel. Whitaker v. Kenosha Unified Sch. Dist. No. 1 Bd. of Educ., 858 F.3d 1034, 1046-54 (7th Cir. 2017); Glenn v. Brumby, 663 F.3d 1312, 1316 (11th Cir. 2011); Schwenk v. Hartford, 204 F.3d 1187, 1201 (9th Cir. 2000); Rosa v. Park W. Bank & Tr. Co., 214 F.3d 213, 215-16 (1st Cir. 2000). District courts across the country have also recognized that discrimination against transgender individuals because their gender identity diverges from their sex assigned at birth violates the plain text of Section 1557. See Tovar v. Essentia Health, 342 F. Supp. 3d 947, 953 (D. Minn. 2018); Flack v. Wis. Dep't of Health Servs., 328 F. Supp. 3d 931, 951 (W.D. Wis. 2018); Prescott v. Rady Children's Hosp.-San Diego, 265 F. Supp. 3d 1090, 1098–1100 (S.D. Cal. 2017). Given the extensive legal precedent, the Department cannot simply assert by regulation that covered entities will not be liable for gender identity discrimination claims where such discrimination is prohibited by the statutory text.

In Hawai'i, prior to 2017, many if not most health insurance plans contained discriminatory categorical exclusions for gender transition-related care, even in plans under which the same treatment would be covered for reasons unrelated to gender transition. Recognizing the life-threatening impact of this discrimination, the Hawai'i State Legislature passed Act 135, which prohibits these exclusions and other forms of discrimination on the basis of gender identity or expression in the health insurance context. While the Current Rule had not yet been finalized at the time of Act 135's passage, the legislative history of Act 135 makes clear that the Current Rule served as a guide for addressing this discrimination. Clear, detailed federal regulations would be helpful to state agencies enforcing this state law as well as members of the public, who need to know their rights.

Further, while the preamble to the Proposed Rule spends an inordinate amount of time attempting to justify the elimination of gender identity as an identified form of sex

discrimination, it does not explain why the other definitional provisions are eliminated as well. Removing the definition of sex discrimination cannot change the underlying legal precedent that the current definition was based on and that still prohibits discrimination on the enumerated bases, including discrimination based on sex stereotyping, pregnancy discrimination, and pregnancy-related conditions. For example, the provision of Hawaii's employment law prohibiting discrimination because of sex explicitly includes discrimination "because of pregnancy, childbirth, or related medical conditions..." Haw. Rev. Stat. § 378-1. As noted by the Hawai'i Supreme Court in *Teague v. Hawai'i Civil Rights Comm'n*, 971 P.2d 1104 (Haw 1999) (holding that appellant's "no leave" policy discriminated against a pregnant employee on the basis of sex), the definition of "because of sex" was amended in 1981 to "clarif[y] and strengthen ... the existing statutory prohibition against employment discrimination because of sex." Sen. Stand. Comm. Rep. No. 1109, in 1981 Senate Journal, at 1363. Additionally, Hawai'i laws prohibiting sex-based discrimination in employment, housing, and public accommodations explicitly include as a part of "sex" gender identity and expression. *See* Haw. Rev. Stat. §§ 378-2, 515-3, and 489-3.

To the extent there is variance among Hawai'i law and federal courts as to what constitutes discrimination based on sex, the Current Rule provides crucial uniformity.

3. HHS should not import an abortion exemption into its definition of sex discrimination.

The Proposed Rule would unnecessarily incorporate the abortion exemption from Title IX into regulations implementing Section 1557. Incorporating the abortion exemption violates the text and purpose of Section 1557, which prohibits discrimination "on the *ground[s]* prohibited under" the referenced civil rights statutes, not the attendant exemptions contained in those statutes. 42 U.S.C. § 18116 (emphasis added). Congress has already spoken clearly as to the restrictions it intended to place on abortion care and coverage, through both the ACA itself, *see* 42 U.S.C. § 18023(b)(1)(A), (b)(4), as well as the Weldon, Church, and Coats Amendments. Abortion care is health care related to pregnancy, and targeting it for exclusion undermines and stigmatizes access to care that is a constitutionally protected right.

Taken as a whole, the Proposed Rule strips explicit regulatory protections for LGBT individuals and for people who require reproductive health care, indicating that the underlying purpose for the amendments is to target transgender and non-binary individuals, as well as other people who face sex-based discrimination in accessing health care and insurance coverage. That is neither consistent with the text of the statute, nor the appropriate mission of the Department.

The Proposed Rule is also untimely, as the U.S. Supreme Court granted petitions for review in three cases addressing whether sex discrimination encompasses discrimination based on sexual orientation, gender identity, and discrimination against transgender individuals due to sex stereotyping under Title VII. *Altitude Exp., Inc. v. Zarda*, 139 S. Ct. 1599 (2019); *Bostock v. Clayton Cty., Ga.*, 139 S. Ct. 1599 (2019); *R.G. & G.R. Harris Funeral Homes, Inc. v. EEOC*, 139 S. Ct. 1599 (2019). Because Title IX generally adopts the standards for discrimination under Title VII, the Department will need to address the practical implications of any decision by the

Court through a renewed comment process. Accordingly, the Department should abandon the Proposed Rule and instead leave in place the existing rule that discrimination based on gender identity is a form of sex discrimination, as is discrimination based on pregnancy, false pregnancy, termination of pregnancy, or recovery therefrom, childbirth or related medical conditions, and sex stereotyping.

B. HHS Should Not Weaken Protections for People with Disabilities.

Historically, people with disabilities in the United States have been unable to access the health care they need because of discrimination by the health insurance industry. Prior to the ACA, people with disabilities were commonly denied or terminated from health coverage, faced annual and lifetime benefit limits, and could not find affordable coverage. Access to adequate health care at affordable rates is central to the ability of disabled people to participate fully in society.

The Department proposes to eliminate Section 92.207 of the Current Rule in its entirety, which would undermine the right of people with disabilities to challenge discriminatory benefit design. Under the Current Rule, for example, plans that cover bariatric surgery in adults but exclude such coverage for adults with particular developmental disabilities, place most or all drugs that treat a specific condition on the highest cost tiers, or exclude bone marrow transplants regardless of medical necessity, constitute disability discrimination in violation of Section 1577. The Department claims that the provision is redundant or may be confusing in relation to the Department's preexisting regulations. But the Current Rule is needed precisely because existing laws were insufficient to dismantle barriers to adequate health insurance for people with disabilities. The deletion thus contravenes Section 1557's plain language.

The application of antidiscrimination principles to health insurers and to benefit design is essential to the needs and rights of disabled people. The Proposed Rule does not apply those principles and should not be adopted.

C. HHS should not weaken protections for individuals with Limited English Proficiency.

The Department should not eliminate the language access protections as described by the Proposed Rule. In Hawai'i, there are 163,995 people with limited English proficiency ("LEP"), and they should all have meaningful access to health care and coverage. Language assistance is necessary to ensure that LEP persons are guaranteed such access, and is a critical protection to combat discrimination on the basis of national origin, which encompasses discrimination on the basis of language.

The Proposed Rule would eliminate significant protections for LEP persons by removing the requirement that covered entities provide notices of legal rights and in-language taglines on significant publications. The taglines are cost-effective ways to maintain access for LEP individuals without translating entire documents. The Department ignores the impact on LEP individuals should this requirement be eliminated, relying solely on reports from health plans, with no public outreach to determine the impact of the taglines or to explore alternatives.

Likewise, the Department should not eliminate references to language access plans, which are a useful tool for covered entities to fully plan how to meet the needs of LEP patients and consumers. Such plans also support covered entities' own compliance efforts, benefiting both LEP individuals and covered entities alike.

LEP individuals face unique risks and barriers to knowing and asserting their rights in the health care context. In 2013, the Hawai'i State Office of Language Access reported in its publication, "Untold Stories" that LEP individuals in the state routinely face barriers to care due to denied access to interpreters and translators. One story detailed the account of an elderly LEP man had to go to the emergency room and was accompanied by his daughter. The daughter continuously requested an interpreter and was denied one. Instead, the hospital forced the daughter to serve as an interpreter. After the man was admitted and the daughter had to go home, the man received a blood transfusion and suffered a negative reaction to the transfusion. He tried to alert medical staff to the complication but no one understood because he still had not been provided an interpreter. It was fortunate that the daughter returned to the hospital before the man suffered even more severe complications from delayed care. Another account tells the story of a mother who is LEP and who was not provided an interpreter during her labor and delivery. This led to the hospital listing *her* name instead of her baby's name on the birth certificate because she was asked to sign a form that she did not understand. Had the individuals in these stories known their legal rights, these negative consequences may have been avoided.

The proposed elimination of protections to aid communication with LEP individuals—both while they are accessing services and so that they know their rights—should be abandoned.

II. THE DEPARTMENT SHOULD NOT LIMIT THE BROAD IMPACT OF SECTION 1557.

The Proposed Rule includes several provisions that would so limit Section 1557's application as to render its protections a nullity for the very people Congress sought to protect. The proposal inappropriately limits the statute's reach in several respects and, as such, the Department should decline to finalize the Proposed Rule, leaving in place the Current Rule.

A. HHS Should Not Import a Religious Exemption into Section 1557.

The Proposed Rule wrongly would allow religiously affiliated healthcare providers to discriminate based on sex and to refuse access to necessary medical care, by importing Title IX's expansive religious exemptions into Section 1557. Religiously affiliated healthcare providers make up a significant percentage of the healthcare facilities in the United States. One in six patients is now treated in a Catholic facility each year, and religious hospitals are also increasingly the *only* health care option in many regions.

Since 2005, there has been at least one rural hospital merger in Hawai'i. Were the Proposed Rule to be finalized, the threat of mergers—particularly, rural mergers—would be dangerous. According to the 2018 Hawai'i Physician Workforce Assessment, there is already a

shortage of medical care providers available to Hawai'i residents. If one of Hawaii's existing hospitals were to merge with a religiously-affiliated hospital, sweeping religious exemptions would be burdensome and potentially life-threatening for patients. Patients turned away pursuant to a religious exemption may be forced to fly to another island for care, which may require the patient to take time off from work and incur the cost of childcare, airfare, and lodging. It would also delay medical treatment.

The proposed religious exemption violates the text and purpose of Section 1557, as well as the constitutional commitment to the separation of church and state. The statute prohibits discrimination "on the *ground[s]* prohibited under" the referenced civil rights statutes, 42 U.S.C. § 18116 (emphasis added), but does not incorporate the attendant exemptions contained in those statutes—many of which are wholly inapposite to the health care context. The Department should not reverse course by incorporating the exemption, having initially rejected invitations to do so. Further, the First Amendment forbids government action favoring religion to the point of forcing third parties to bear the costs of those beliefs. *See Estate of Thornton v. Caldor, Inc.*, 472 U.S. 703, 708–10 (1985). The Proposed Rule's exemption flies in the face of the careful balance courts have struck between civil rights and religious liberty, running afoul of the Establishment Clause.

Permitting a blanket religious exemption to Section 1557's nondiscrimination mandate threatens access to critical care for countless patients, especially transgender patients and patients seeking reproductive health services. The Proposed Rule altogether fails to consider the harmful consequences of importing a broad religious exemption into the health care context.

B. HHS Should Not Narrow the Scope of Covered Entities.

The Proposed Rule would further undercut Section 1557 by limiting the entities covered by the provision. Limiting the application of Section 1557's protections would sanction discriminatory denials of coverage by entities that are presently covered by Section 1557, causing confusion and serious harm to those unable to access care. Additionally, the Proposed Rule displays no awareness of the potential harm to individuals denied coverage of and access to health care due to the proposed limitations on Section 1557's application.

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without cohesive, uniform procedures for investigating grievances. Further, the Department should not eliminate the explicit requirement that such procedures "incorporate appropriate due process standards," which provides that the procedures in place are sufficient to address claims of discrimination promptly and equitably. 45 CFR 92.7. Likewise, the Department should not eliminate the requirement that covered entities provide notice to the public that they do not discriminate, as the current procedure is crucial to ensure that individuals are aware of the safeguards in place and of the steps they can take to effectuate the protections under Section 1557. 45 CFR 92.8. The costs associated with the notice requirement are well worth the benefit of ensuring that protected individuals receive adequate notice of their rights.

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For all these reasons, the Department should withdraw the Proposed Rule.

Sincerely,

Amanda Fernandes Policy Director ACLU of Hawai'i Case 1:20-cv-05583-AKH Document 76-1 Filed 09/17/20 Page 30 of 73



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August 13, 2019

U.S. Department of Health and Human Services Office for Civil Rights Attention: Section 1557 NPRM, RIN 0945-AA11 Hubert H. Humphrey Building, Room 509F 200 Independence Avenue SW Washington, DC 20201

Submitted electronically

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The ACLU of IL, and its affiliated Roger Baldwin Foundation (RBF), are non-partisan, non-profit organizations dedicated to protecting the liberties guaranteed by the U.S. Constitution, the state Constitution, and state/federal human rights laws. We accomplish these goals through litigating, lobbying and educating the public on a broad array of civil liberties issues. Among those are our continued advocacy efforts to combat discrimination and expand access to health care for all people. With a growing membership in Illinois and across the country, we are among countless other advocates who recognize the need for our state and national laws to protect equal access to health care.

The rule currently in place implementing Section 1557, titled "Nondiscrimination in Health Programs and Activities" (the "Current Rule"), was developed after years of review and consideration of comments from a variety of stakeholders. The Current Rule meets a critical need and fulfills Congress's intent to provide "equal access to health services and health insurance that all individuals should have, regardless of their race, color, national origin, age, or disability." 81 Fed. Reg. 31,459. Discrimination in the health care context leads to lasting harms to people's health and wellbeing, and the Department of Health and Human Services (the "Department" or "HHS") made detailed factual findings to that effect in support of the Current Rule: People subject to discrimination postpone or fail to obtain health services and are denied necessary care; such discrimination exacerbates health disparities in underserved communities.

The Proposed Rule, however, is yet another attempt by the Trump Administration and the Department to undermine access to health care for the most vulnerable individuals and

communities, while emboldening discriminatory and dangerous denials of care. The Proposed Rule's explicit reductions in the scope of antidiscrimination protections, as well as the implicit invitation for health care providers to undermine access to care, completely disregard the potential harms to individuals trying to access health care and coverage. This approach is contrary to the statutory language of Section 1557, and is a reversal of the reasoned policy decisions of the Current Rule. Further, it will fail to accomplish its stated goal to *decrease* confusion, instead *increasing* the burdens and costs of compliance.

For these reasons, as well as the ones that follow, the ACLU of Illinois recommends that the Department decline to finalize the Proposed Rule in its entirety.

I. THE PROPOSED RULE SHOULD NOT ROLL BACK AFFIRMATIVE ANTIDISCRIMINATION PROTECTIONS.

The Proposed Rule includes a general prohibition against discrimination on the basis of race, color, national origin, sex, age and/or disability; but it removes detailed prohibitions against specific forms of discrimination that spell out what covered entities must do to comply. The move will prevent already marginalized populations from accessing health care and insurance. The Current Rule encouraged affirmative antidiscrimination protections. To that end, Illinois made significant changes to its Medicaid program over the last few years, including providing abortion coverage, and coverage for medical treatment of gender dysphoria. ¹

A. HHS Should Maintain the Existing Definition of Discrimination on the Basis of Sex and Protections Against Such Discrimination.

In promulgating the Current Rule, the Department recognized the importance of affirmative regulatory protections—specifically for all enumerated forms of sex discrimination. The Current Rule defines discrimination based on sex to include discrimination on the basis of pregnancy, false pregnancy, termination of pregnancy, or recovery therefrom, childbirth or related medical conditions, sex stereotyping, and gender identity. 45 CFR 92.4. The Proposed Rule eliminates this key provision that clarifies what discrimination on the basis of sex encompasses, and removes explanatory examples of prohibited activity. The Proposed Rule also amends regulations—and incorporates an abortion exemption—that are unrelated to Section 1557. These changes are without justification and will directly harm patients seeking care.

1. The proposed amendments abandon LGBT individuals and people seeking reproductive health care, who depend on HHS to protect their statutory rights.

Section 1557 and the Current Rule are intended to protect people from the pervasive problem of sex-based discrimination in the health care context. Lesbian, gay, bisexual, and transgender ("LGBT") patients, as well as people who seek or have obtained reproductive health services, face discrimination based on sex in accessing health care. This discrimination can

¹ Pub. Act 100-0538 (eff. Jan 1, 2018); https://www.aclu-il.org/en/press-releases/aclu-illinois-applauds-new-rules-cover-gender-affirming-surgery-under-states-medicaid

range from providers using harassing or abusive language to completely refusing necessary medical care. Sex-based exclusions from health care coverage can also make essential medical care unaffordable. For example, some transgender and non-binary individuals are subject to discriminatory categorical exclusions for health care related to gender transition that put necessary health care out of financial reach.

A transgender man working as a bus operator for the Chicago Transit Authority ("CTA") recently experienced discrimination through his employer-sponsored health insurance. He began medically transitioning in July 2016 and made the decision to get reconstructive chest surgery in 2017. Yet, he was initially denied coverage of the surgery because his CTA insurance policy excluded coverage of reconstructive chest surgery except for patients with cancer. The ACLU of IL sent a letter on his behalf demanding that the CTA comply with federal and state law requirements that insurance policies cover necessary medical procedures, including gender-affirming surgical treatment for employees who are transgender. As a result, the CTA removed the discriminatory exclusion from their insurance policy

Rolling back affirmative antidiscrimination protections would severely limit an individual's ability to challenge unfair and discriminatory policies and inhibit access to health care. By eliminating the definition of discrimination on the basis of sex, as well as stripping protections against discrimination based on gender identity and sexual orientation from other unrelated HHS regulations, the Proposed Rule will invite such discrimination against LGBT individuals and people seeking reproductive health care.

The Department fails to even consider the impact that the Proposed Rule would have on individuals who are protected under the Current Rule. In a 2016 survey, roughly 50,000 people identified as transgender in the state of Illinois. The Department must prioritize the impact that inviting discrimination against patients will have on public health, particularly the harms to transgender and non-binary individuals, as well as people who need or have obtained pregnancy-related health services, all of whom would no longer have explicit regulatory protections against sex discrimination if the Proposed Rule is finalized.

2. The proposed amendments do not provide clarity, but only create more confusion.

The Department contends that the Proposed Rule is needed to reduce confusion and to clarify the scope of Section 1557. But should the Department delete the definitional provisions, it would actually *cause* confusion and embolden health care and insurance providers to discriminate. The Department's proposal does nothing to clarify what constitutes prohibited sex discrimination under Section 1557, as eliminating the definition does not mean that discrimination on the presently enumerated bases is suddenly permitted. Instead, eliminating the definition invites discrimination and undermines uniformity among providers—to the detriment of covered entities and patients alike.

Because discrimination based on sex would still be prohibited, discrimination based on gender identity would remain unlawful under Section 1557 as well. Courts have consistently held that Title IX's prohibition on sex discrimination protects individuals from discrimination based on gender nonconformity. *See EEOC v. R.G. &. G.R. Harris Funeral Homes, Inc.*, 884 F.3d 560, 572 (6th Cir. 2018), *cert. granted in part*, 139 S. Ct. 1599 (2019); *Whitaker ex rel.*

Whitaker v. Kenosha Unified Sch. Dist. No. 1 Bd. of Educ., 858 F.3d 1034, 1046–54 (7th Cir. 2017); Glenn v. Brumby, 663 F.3d 1312, 1316 (11th Cir. 2011); Schwenk v. Hartford, 204 F.3d 1187, 1201 (9th Cir. 2000); Rosa v. Park W. Bank & Tr. Co., 214 F.3d 213, 215–16 (1st Cir. 2000). District courts across the country have also recognized that discrimination against transgender individuals because their gender identity diverges from their sex assigned at birth violates the plain text of Section 1557. See Tovar v. Essentia Health, 342 F. Supp. 3d 947, 953 (D. Minn. 2018); Flack v. Wis. Dep't of Health Servs., 328 F. Supp. 3d 931, 951 (W.D. Wis. 2018); Prescott v. Rady Children's Hosp.-San Diego, 265 F. Supp. 3d 1090, 1098–1100 (S.D. Cal. 2017). Given the extensive legal precedent, the Department cannot simply assert by regulation that covered entities will not be liable for gender identity discrimination claims where such discrimination is prohibited by the statutory text.

Further, while the preamble to the Proposed Rule spends an inordinate amount of time attempting to justify the elimination of gender identity as an identified form of sex discrimination, it does not explain why the other definitional provisions are eliminated as well. Removing the definition of sex discrimination cannot change the underlying legal precedent that the current definition was based on and that still prohibits discrimination on the enumerated bases, including discrimination based on sex stereotyping, pregnancy discrimination, and pregnancy-related conditions.

For example, the Illinois Human Rights Act ("IHRA") prohibits discrimination on the basis of "gender-related identity, whether or not traditionally associated with the person's designated sex at birth." The IHRA is intended to "promote the public health, welfare and safety by protecting the interests of all people in Illinois in maintaining personal dignity, in realizing their full productive capacities, and in furthering their interests, rights, and privileges as citizens of this State." Both the Illinois Human Rights Commission and state courts have recognized that discrimination based on sex encompasses discrimination on the basis of pregnancy, sex stereotyping, sexual orientation and gender identity. Both have also applied the same three-step prima facie analysis for a pregnancy-based sex discrimination claim, for example, as they have for a sex stereotyping case. To the extent there is variance among Illinois laws and federal courts as to what constitutes discrimination based on sex, the Current Rule provides crucial uniformity.

3. HHS should not import an abortion exemption into its definition of sex discrimination.

The Proposed Rule would unnecessarily incorporate the abortion exemption from Title IX into regulations implementing Section 1557. Incorporating the abortion exemption violates the text and purpose of Section 1557, which prohibits discrimination "on the *ground[s]* prohibited under" the referenced civil rights statutes, not the attendant exemptions contained in

² See P.A. 93-1078, eff. Jan. 1, 2006, codified at 775 ILCS 5/1-103 (O-1).

 $^{^{3}}$ *Id.* at 5/102(E).

⁴ In the Matter of: Patricia Diciolla, 1996 WL 379349, at 9; In the matter of: Meggan Sommerville, and Hobby Lobby Stores, Inc., 2019 WL 2024088, at 25

⁵ Ellis and Brunswick Corporation, 31 III. HRC Rep. 326 (1987); Foley v. Illinois Human Rights Commission, 165 III.App.3d 594, 519 N.E.2d 129 (5th Dist. 1988); Loyola University of Chicago v. Illinois Human Rights Commission, 149 III.App.3d 8, 500 N.E.2d 639, 102 III.Dec. 746 (1st Dist., 3rd Div. 1986).

those statutes. 42 U.S.C. § 18116 (emphasis added). Congress has already spoken clearly as to how it intended to regulate abortion care and coverage, through both the ACA itself, *see* 42 U.S.C. § 18023(b)(1)(A), (b)(4), as well as the Weldon, Church, and Coats Amendments. Abortion care is health care related to pregnancy, and targeting it for exclusion undermines and stigmatizes access to care that is a constitutionally protected right.

* * *

Taken as a whole, the Proposed Rule strips explicit regulatory protections for LGBT individuals and for people who require reproductive health care, indicating that the underlying purpose for the amendments is to target transgender and non-binary individuals, as well as other people who face sex-based discrimination in accessing health care and insurance coverage. That is neither consistent with the text of the statute, nor the appropriate mission of the Department. The Proposed Rule is also untimely, as the U.S. Supreme Court granted petitions for review in three cases addressing whether sex discrimination encompasses discrimination based on sexual orientation, gender identity, and discrimination against transgender individuals due to sex stereotyping under Title VII. Altitude Exp., Inc. v. Zarda, 139 S. Ct. 1599 (2019); Bostock v. Clayton Cty., Ga., 139 S. Ct. 1599 (2019); R.G. & G.R. Harris Funeral Homes, Inc. v. EEOC, 139 S. Ct. 1599 (2019). Because Title IX generally adopts the standards for discrimination under Title VII, the Department will need to address the practical implications of any decision by the Court through a renewed comment process. Accordingly, the Department should abandon the Proposed Rule and instead leave in place the existing rule that discrimination based on gender identity is a form of sex discrimination, as is discrimination based on pregnancy, false pregnancy, termination of pregnancy, or recovery therefrom, childbirth or related medical conditions, and sex stereotyping.

B. HHS Should Not Weaken Protections for People with Disabilities.

Historically, people with disabilities in the United States have been unable to access the health care they need because of discrimination by the health insurance industry. Prior to the ACA, people with disabilities were commonly denied or terminated from health coverage, faced annual and lifetime benefit limits, and could not find affordable coverage. Access to adequate health care at affordable rates is central to the ability of disabled people to participate fully in society.

The Department proposes to eliminate Section 92.207 of the Current Rule in its entirety, which would undermine the right of people with disabilities to challenge discriminatory benefit design. Under the Current Rule, for example, plans that cover bariatric surgery in adults but exclude such coverage for adults with particular developmental disabilities, place most or all drugs that treat a specific condition on the highest cost tiers, or exclude bone marrow transplants regardless of medical necessity, constitute disability discrimination in violation of Section 1557. The Department claims that the provision is redundant or may be confusing in relation to the Department's preexisting regulations. But the Current Rule is needed precisely because existing laws were insufficient to dismantle barriers to adequate health insurance for people with disabilities. The deletion thus contravenes Section 1557's plain language.

The application of antidiscrimination principles to health insurers and to benefit design is essential to the needs and rights of disabled people. The Proposed Rule does not apply those principles and should not be adopted.

C. HHS should not weaken protections for individuals with Limited English Proficiency.

The Department should not eliminate the language access protections as described by the Proposed Rule. In Illinois, there are 1,131,389 people with limited English proficiency ("LEP"), and they should all have meaningful access to health care and coverage. Language assistance is necessary to ensure that LEP persons are guaranteed such access, and is a critical protection to combat discrimination on the basis of national origin, which encompasses discrimination on the basis of language.

LEP individuals face unique risks and barriers to knowing and asserting their rights in the health care context. When compared to English-speaking patients, LEP patients traditionally have longer hospital stays when professional interpreters are not used at admissions and/or discharge. 6 LEP patients also have a greater risk of line infections, surgical infections, falls, and pressure ulcers; a greater risk of surgical delays due to difficulty understanding instructions; and a greater chance of readmissions for certain chronic conditions due to difficulty with understanding care management, medications, and knowing which symptoms should prompt a return to care or when to follow up.⁷ Recognizing that communication with one's doctor is critical, Illinois passed the Language Assistance Services Act to ensure access to health care information and services for LEP individuals.⁸ The state also requires mental health facilities to provide interpreters during admission, intake, and evaluation.⁹

Despite protections at the federal and state level, LEP individuals still experienced barriers to accessing the care they needed. The Illinois Advisory Committee to the U.S. Commission on Civil Rights noted that although individuals were guaranteed rights to interpreter services, health facilities were not guaranteed payment providing this service. ¹⁰ The Current Rule requires that covered entities provide notices of legal rights and in-language taglines on significant publications. The taglines are cost-effective ways to maintain access for LEP individuals without translating entire documents. The Proposed Rule would eliminate significant

⁶ The Joint Commission, Division of Health Care Improvement, 13 Quick Safety (May 2015). https://www.jointcommission.org/assets/1/23/Quick_Safety_Issue_13_May_2015_EMBARGOED_5_27_15.pdf (accessed Aug. 6, 2019).

⁷ Id; see also, Joseph R. Betancourt & Aswita Tan-McGrory, Creating a safe, high-quality healthcare system for all: Meeting the needs of limited English proficient populations; Comment on 'Patient safety and healthcare quality: The case for language access, 2 Intl. J. Health Policy and Management, International Journal of Health Policy and Management 2, 91-94 (2014).

⁸ 210 Ill. Comp. Stat. 87/1-19 (2010).

⁹ Ill. Admin. Code tit. 59, § 111.25 (1997); see also 405 ILCS 75 (2000) (The Illinois "Mental Health Hispanic Interpreter Act requires that state-operated mental health and developmental disability facilities—when at least 1 percent of annual admissions for inpatient or outpatient care consist of Hispanic patients—[to] provide qualified interpreters as necessary, including whenever a recipient is admitted or receives care or treatment."). ¹⁰ IL Advisory Committee to the U.S. Commission on Civ. Rights, Health Facilities in Illinois and Patient Access to

Quality Language Interpreters, Oct. 2011. https://www.usccr.gov/pubs/docs/ILSAC_TitleVI%5b1%5d.pdf (accessed Aug. 6, 2019).

protections for LEP persons by removing these requirements. The Department ignores the impact on LEP individuals should this requirement be eliminated, relying solely on reports from health plans, with no public outreach to determine the impact of the taglines or to explore alternatives. Likewise, the Department should not eliminate references to language access plans, which are a useful tool for covered entities to fully plan how to meet the needs of LEP patients and consumers. Such plans also support covered entities' own compliance efforts, benefiting both LEP individuals and covered entities alike.

The proposed elimination of protections to aid communication with LEP individuals—both while they are accessing services and so that they know their rights—should be abandoned.

II. THE DEPARTMENT SHOULD NOT LIMIT THE BROAD IMPACT OF SECTION 1557.

The Proposed Rule includes several provisions that would so limit Section 1557's application as to render its protections a nullity for the very people Congress sought to protect. The proposal inappropriately limits the statute's reach in several respects and, as such, the Department should decline to finalize the Proposed Rule, leaving in place the Current Rule.

A. HHS Should Not Import a Religious Exemption into Section 1557.

The Proposed Rule wrongly would allow religiously affiliated healthcare providers to discriminate based on sex and to refuse access to necessary medical care, by importing Title IX's expansive religious exemptions into Section 1557. Religiously affiliated healthcare providers make up a significant percentage of the healthcare facilities in the United States. One in six patients is now treated in a Catholic facility each year, and religious hospitals are also increasingly the *only* health care option in many regions. In Illinois, that number is closer to 30 percent. This means that roughly one in three hospital beds in the State are Catholic and controlled by broad religious directives. By virtue of where these hospitals are located, there are many areas across the state where the only hospital in close proximity to a patient is religiously affiliated. A look at specific departments reveals even more alarming statistics, with roughly 65 percent of labor and delivery departments in Cook County having a religious affiliation. Section 13

In many cases, patients are either completely unaware that they are going to a religious hospital, or they have no choice because their insurance is connected with a Catholic health care

 $http://static1.1.sqspcdn.com/static/f/816571/27061007/1465224862580/MW_Update-2016-MiscarrOfMedicine-report.pdf?token=KO%2Bv8%2FG6n4LMJ7mdY%2BZldZJyp1s%3D$

¹¹ Louis Uttley and Christine Khaikin, Growth of Catholic Hospitals and Health Systems: 2016 Update of the Miscarriage of Medicine Report, MergerWatch, (2016) (accessed Aug. 6, 2019).

¹² ACLU of Illinois, *Put Patients First* (accessed on Aug. 6, 2019). https://www.aclu-il.org/en/campaigns/put-patients-first

¹³ Sarah Garcia-Ricketts, Lee Hasselbacher, Luciana Hebert & Debra Stulberg, *The Role of Religiously-affiliated Hospitals in Reproductive Health Care for Women with Public Insurance in Cook County, Illinois*, Univ. of Chi. (2018) https://ci3.uchicago.edu/wp-content/uploads/2018/07/The-Role-of-Religiously-affiliated-Hospitals-in-Reproductive-Health-Care-for-Women-with-public-insurance-in-Cook-County.pdf

facility.¹⁴ For instance, between 2015-2017, nearly 9 in 10 women enrolled in Cook County managed care plans were enrolled in a plan that had greater Catholic hospital saturation.¹⁵ Of those, Black and Hispanic/Latino women were significantly more likely to be enrolled in a higher Catholic-saturation plan compared to White women.¹⁶ The implication this has on patient care is vast, because the religious directives under which Catholic hospitals operate restrict a wide range of health care services, including contraception, abortion, and transition-related care.¹⁷

The proposed religious exemption violates the text and purpose of Section 1557, as well as the constitutional commitment to the separation of church and state. The statute prohibits discrimination "on the *ground[s]* prohibited under" the referenced civil rights statutes, 42 U.S.C. § 18116 (emphasis added), but does not incorporate the attendant exemptions contained in those statutes—many of which are wholly inapposite to the health care context. The Department should not reverse course by incorporating the exemption, having initially rejected invitations to do so. Further, the First Amendment forbids government action favoring religion to the point of forcing third parties to bear the costs of those beliefs. *See Estate of Thornton v. Caldor, Inc.*, 472 U.S. 703, 708–10 (1985). The Proposed Rule's exemption flies in the face of the careful balance courts have struck between civil rights and religious liberty, running afoul of the Establishment Clause.

Permitting a blanket religious exemption to Section 1557's nondiscrimination mandate threatens access to critical care for countless patients, especially transgender patients and patients seeking reproductive health services. The Proposed Rule altogether fails to consider the harmful consequences of importing a broad religious exemption into the health care context. In recent years, a number of such cases where patients were denied necessary medical care at religious institutions, have been brought through various channels in Illinois, as described below:

- A patient was denied proper treatment for a miscarriage at a hospital that follows religious restrictions – an experience that placed her life and health at unnecessary risk
- When a patient's IUD became dislodged, it caused her bleeding and pain. She went
 to her doctor, but was told that nothing could be done because of the religious
 restrictions imposed on the Catholic practice, among them being the removal of her
 IUD. From the day her IUD was dislodged, it took the patient more than two weeks

¹⁴ Amelia Thomson-DeVeaux and Anna Maria Barry-Jester, *Insurers Can Send Patients To Religious Hospitals That Restrict Reproductive Care*, FiveThirtyEight (Aug. 1, 2018). https://fivethirtyeight.com/features/how-insurers-can-send-patients-to-religious-hospitals-that-restrict-reproductive-care/ (accessed on Aug. 12, 2019).

¹⁵ Sarah Garcia-Ricketts, Lee Hasselbacher, Luciana Hebert & Debra Stulberg, *The Role of Religiously-affiliated Hospitals in Reproductive Health Care for Women with Public Insurance in Cook County, Illinois*, Univ. of Chi. (2018) https://ci3.uchicago.edu/wp-content/uploads/2018/07/The-Role-of-Religiously-affiliated-Hospitals-in-Reproductive-Health-Care-for-Women-with-public-insurance-in-Cook-County.pdf (prior to the 2018 reboot of HealthChoice Illinois, 87 percent of the female residents of Cook County, between the ages of 19 and 44, were in one of the five higher Catholic-saturated plans offered by the program).

 $^{^{17}}$ U.S. Conference of Catholic Bishops, Ethical Religious Directives for Catholic Health Care Services (6th ed. 2018)

http://www.usccb.org/about/doctrine/ethical-and-religious-directives/upload/ethical-religious-directives-catholic-health-service-sixth-edition-2016-06.pdf

- to actually have it removed because of the breadth of limitations imposed in religious health care facilities.
- Another patient was denied basic contraceptive care by a Catholic health care provider to whom a Medicaid Managed Care Organization referred her. At the appointment, not only was the patient denied the contraceptive care she needed, she was also scolded for not wanting to be a parent and told that all women "should be required" to have children. It was not until she set up two more appointments, with the final one being at a non-religious facility, that she finally received the care she needed.
- A patient developed a pregnancy plan with her doctor that included a tubal ligation. However, it was not until she had been in labor for three full days and was being wheeled in for a Cesarean section that the patient learned that her doctor's practice had been purchased by a Catholic provider and therefore subject to its restrictive religious directives. She was denied her tubal ligation, despite having it in her pregnancy plan, was given no prior notice about the change, and was also later denied contraception.

Despite Illinois' recent passage of the Reproductive Health Act, which enshrines reproductive health care as a fundamental right, there are still many ways in which access to contraception, sterilization, and abortion can be threatened. The Proposed Rule would be just another means restrict access to reproductive health care in the name of religion.

B. HHS Should Not Narrow the Scope of Covered Entities.

The Proposed Rule would further undercut Section 1557 by limiting the entities covered by the provision. Limiting the application of Section 1557's protections would sanction discriminatory denials of coverage by entities that are presently covered by Section 1557, causing confusion and serious harm to those unable to access care. Additionally, the Proposed Rule displays no awareness of the potential harm to individuals denied coverage of and access to health care due to the proposed limitations on Section 1557's application.

Excluding health insurance from Section 1557's nondiscrimination mandate as distinct from "health program or activity" is contrary to the text of the statute and the broader antidiscrimination purpose of the law. The false distinction is exacerbated by the Proposed Rule's new limitation on the application of Section 1557 in cases where the entity is not "principally engaged in the provision of health care." In such cases, under the proposal, Section 1557 would apply only to the specific operations of an entity that receive federal financial assistance—whereas Section 1557 covers *all* operations of entities principally engaged in health care that receive federal financial assistance. This distinction, too, is contrary to the text of the statute, which prohibits discrimination under "any health program or activity, *any part of which* is receiving Federal financial assistance." 42 U.S.C. § 18116 (emphasis added).

C. HHS Should Maintain Existing Remedies Available for Section 1557 Claims.

The Current Rule adopts a uniform standard, applicable to all grounds covered by Section 1557, and incorporates enforcement mechanisms that exist under any of the civil rights laws referenced by Section 1557. This includes a private right of action for disparate-impact claims and the availability of compensatory damages for all claims under Section 1557. In removing

these provisions, the proposed rule creates a scheme in which people are denied certain legal remedies because of the type of discrimination they experience. Such a change also privileges purported business interests in relieving regulatory burdens over the interests of the public and of individuals seeking health care. However, by removing the certainty of the Current Rule, covered entities and protected individuals alike would be uncertain as to the law's requirements and protections, instead leaving them to look to four other separate civil rights laws and various agencies' implementing regulations for clues.

The Proposed Rule's silence regarding the availability of a private right of action is at worst contrary to the rights-expanding aims of the statute and, at best, purposeless. Parties asserting private rights of action pursuant to Section 1557 have significantly expanded access to health care and combatted discriminatory health care policies, and will continue to do so, regardless of regulatory language explicitly affirming that such a right exists.

The Department should also not eliminate the Current Rule's provision for disparate-impact claims, which promotes better compliance with Section 1557's nondiscrimination provisions. The disparate-impact mechanism encourages health care providers to identify disparities and to adopt solutions that make a crucial difference in eliminating those disparities for individuals and improving public health.

These enforcement mechanisms are particularly important for people of color. Addressing racial disparities in health care is a matter of life and death. Such disparities are found across a range of illnesses and health care services, even when accounting for socioeconomic factors. Disparities in health care also have historic roots. As in other sectors of society, segregated health care was once sanctioned by law, and government-sanctioned discrimination continues to have a systemic impact on access to quality health care. At the same time, research suggests that many racial and ethnic health disparities could be reduced or even eliminated if identified and addressed. A disparate-impact private right of action is a crucial enforcement mechanism to confront and redress discrimination.

The Department's proposal would instead make enforcement more difficult, and would increase confusion as to the scope of Section 1557's protections. The Department should accordingly continue to affirm existing enforcement mechanisms, including the private right of action for disparate-impact claims.

D. The Department Should Not Eliminate Grievance Procedures and Notice Requirements.

The Proposed Rule would unnecessarily eliminate the specific grievance procedures established under Section 1557, which would leave covered entities and impacted individuals without cohesive, uniform procedures for investigating grievances. Further, the Department should not eliminate the explicit requirement that such procedures "incorporate appropriate due process standards," which provides that the procedures in place are sufficient to address claims of discrimination promptly and equitably. 45 CFR 92.7. Likewise, the Department should not eliminate the requirement that covered entities provide notice to the public that they do not discriminate, as the current procedure is crucial to ensure that individuals are aware of the safeguards in place and of the steps they can take to effectuate the protections under Section

1557. 45 CFR 92.8. The costs associated with the notice requirement are well worth the benefit of ensuring that protected individuals receive adequate notice of their rights.

III. THE PROPOSED RULE VIOLATES SECTION 1554 OF THE ACA.

The Proposed Rule is additionally contrary to law because it violates another provision of the ACA: Section 1554. This provision limits the Department's rulemaking authority, prohibiting HHS from promulgating regulations that create any unreasonable barriers to the ability of individuals to obtain appropriate medical care, impede timely access to health care services, violate the ethical standards of health care professionals, or limit the availability of health care treatment for the full duration of a patient's medical needs—among other restrictions. 42 U.S.C. § 18114. For all the reasons outlined in this comment, the Proposed Rule represents a direct violation of Congress's command and should be entirely abandoned.

* * *

For all these reasons, the Department should withdraw the Proposed Rule.

Sincerely,

/s/ Colleen Connell

Colleen Connell Executive Director

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August 12, 2019

Via Electronic submission at www.regulations.gov

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Re: Nondiscrimination in Health and Health Education Programs or Activities, Docket No.: HHS-OCR-2019-0007, RIN 0945-AA11

Dear Mr. Severino:

Washington, DC 20201

The Association of American Medical Colleges (AAMC) appreciates the opportunity to provide comments on the Centers for Medicare and Medicaid, Office for Civil Rights, and Office of the Secretary proposed rule, *Nondiscrimination in Health and Health Education Programs or Activities,* 84 *FedReg* 27846 (June 14, 2019). The AAMC is a not-for-profit association representing all 154 accredited U.S. medical schools and 17 accredited Canadian medical schools, nearly 400 major teaching hospitals and health systems, including 51 Department of Veterans Affairs medical centers, and more than 80 academic and scientific societies. Through these institutions and organizations, the AAMC represents more than 173,000 faculty members, 89,000 medical students, 129,000 resident physicians, and more than 60,000 graduate students and postdoctoral researchers in the biomedical sciences.

Our members are key health care providers to their communities and are strongly committed to treating all patients and families with respect and providing the highest quality, most equitable care. The comments below reflect our concerns that the proposed changes to regulations that implement section 1557 of the Affordable Care Act (ACA; 42 USC §18816) will harm patients and their families; exacerbate existing inequities in health and health care in the communities served by our members; and may leave the providers who care for these patients without payment for that care.

In our October 2015 letter in response to the initial Notice of Proposed Rulemaking (RIN 0945-AA02), the AAMC voiced strong support for the HHS proposal to extend nondiscrimination protections to transgender populations and to strengthen protections for persons living with disability and those with limited English proficiency (LEP). Further, we encouraged HHS to explicitly include lesbian, gay and bisexual individuals in the definition of "sex" proffered in the rule. We voiced this support and encouragement based, in part, on the endemic inequities in health and health care experienced by those populations in the face of decreased health care access, implicit and explicit bias within the health care system, and pervasive stigma and discrimination.

Ultimately, implementation of the final rule was blocked in July 2017, and in the intervening two years not only have those inequities persisted, but for some groups – transgender women of color in

particular – the situation has worsened. ¹ To ensure that regulations reflect the broad scope of section 1557 that "an individual shall not . . . be excluded from participation in, be denied the benefits of, or be subject to discrimination under, any health care program or activity that is administered by an Executive Agency or any entity established under this title . . ." the AAMC urges HHS to withdraw the proposed changes to the Section 1557 regulations.

More specific comments follow.

To clearly and consistently implement Section 1557 and ensure that the regulations reflect the clear meaning of the statute, the definitions of "on the basis of sex" and "covered entity" should not be changed.

Definitions are essential for the appropriate implementation of section 1557 requirements. Given the extensive comments that were received in response to the proposed definitions, including those of "on the basis of sex" and "covered entity" (see 81 FedReg 31376, May 19, 2019) it is clear that definitions are needed to ensure a consistent understanding of the application and enforcement of the regulation.

As HHS noted in the preamble to the final 2016 rule, "we sought comment on the best way of ensuring that this rule includes the most robust set of protections supported by the courts on an ongoing basis." (81 FedReg 31388). The AAMC was disappointed that the final rule did not add gender identity and gender expression to the definition of "on the basis of sex." While the proposed rule cites the Franciscan Alliance case to bolster this proposal, "every district court that has considered this issue [regarding that "on the basis of sex" includes discrimination based on "gender identity and "termination of pregnancy"] over the past two years has concluded that discrimination against transgender individuals is prohibited by Section 1557 itself (rather than the regulation)."²

The proposed revisions to Section 1557 regulations would limit the scope of the application of the rule to "entities with a health program or activity, any part of which receives Federal financial assistance from the Department" (p. 27877). It would also exclude short term limited duration insurance. The impact of these limitations on Section 1557 will mean that individuals will not have the protections afforded to them that were intended by Congress when it enacted the legislation.

The AAMC notes Section VIII of the proposed role provides a list of issues for which it is requesting comments, many of which focus on the <u>costs</u> of the current rule. However, there is no attempt by HHS to consider the <u>benefits</u> that will accrue to individuals who are protected by the rule. As was noted in the 2016 final rule:

In enacting Section 1557 of the ACA, Congress recognized the benefits of equal access to health services and health insurance that all individuals should have, regardless of their race, color, national origin, age, or disability. Section 1557 brought together the rights to equal access that had been guaranteed under Title VI, the Age Act and Section 504. At the

¹ A National Epidemic: Fatal Anti-Transgender Violence in America in 2018 https://www.hrc.org/resources/a-national-epidemic-fatal-anti-transgender-violence-in-america-in-2018 Accessed 8/6/19.

² HHS Proposes to Strip Gender identity, Language Access protections from ACA Anti-Discrimination Rule, Katie Keith, Health Affairs Blog, 10.1377/hblog20190525.831858, May 25, 2019.

same time, Congress extended these protections and rights to individuals seeking access to health services and health insurance without discrimination on the basis of sex. (p. 31459)

In the final rule Table 7-Accounting Statement, noted as qualitative benefits, "potential health improvements and longevity extensions as a result of reduced barriers to medical care for transgender individuals." (p. 31465)

AAMC strongly opposes the removal of any and all discrimination prohibitions from the rule

While AAMC is glad to see that OCR proposes to maintain protections for persons living with disability, we oppose the roll back of protections for the LBGTQ population.

According to the <u>Centers for Disease Control and Prevention</u> (CDC), the LGBTQ community experiences significant inequities across a wide array of health and health care outcomes, including (but not limited to) tobacco use, depression, and HIV infection for gay and bisexual men; obesity, gynecological cancer, and heart disease for lesbian and bisexual women; and lack of insurance coverage, suicidality, and exposure to violence for transgender persons.

While multiple factors influence the development of these unjust and avoidable differences in health between the LGBTQ population and their heterosexual/cisgender counterparts, stigma, discrimination, and trans/homophobia in health care is a significant contributor. AAMC's own research shows that members of the LGB community are more likely than heterosexuals to report they do not feel respected by their health care provider.

There is no cost benefit to hospitals associated with permitting discrimination. There is no burden reduction related to sanctioning bias. The only outcomes of greenlighting systematic bigotry in health care will be to increase fear of discrimination, decrease health care access and use for the LGBTQ community, and widen already unconscionable health inequities.

HHS' stated mission is to "enhance and protect the health and well-being of all Americans". The AAMC encourages HHS to follow through on that promise and reject discrimination in health care.

There is no need to expand religious exemptions

HHS proposes that Section 1557 should incorporate abortion and religious exemptions contained in Title IX.

As we stated when we commented on the original 2008 Federal Health Care Conscience Rule, no individual or entity in this country has the option to pick and choose the laws to which he/she will adhere. Every health care provider and entity already has the obligation to comply with all applicable

³ Health and Care Utilization of Transgender and Gender Nonconforming Youth: A Population-Based Study. G. Nicole Rider, Barbara J. McMorris, Amy L. Gower, Eli Coleman, Marla E. Eisenberg Pediatrics Mar 2018, 141 (3) e20171683; DOI: 10.1542/peds.2017-1683.

⁴Dill, Michael J. 2014. "Sexual Orientation, Access to Care and Patient-Provider Communications." AAMC Health Workforce Research Conference. Washington, D.C.

federal laws. The Department has offered little evidence that this has not been the case. The Office of Civil Rights has received just forty-four complaints since it was designated with authority to enforce the Church, Coats-Snow, and Weldon Amendments. The paucity of complaints does not provide compelling evidence of a need for the expansion of OCR's authority, or the need for changes in the current regulations.

As the preamble to the proposed rule demonstrates, statutes and regulations already exist that broadly provide for religious exemptions. There is no need for additional exemptions.

Further, AAMC wishes to restate its concern that religious exemptions, particularly for family planning, will do harm to lower income Americans, racial and ethnic minorities, the LGBTQ community, and patients in rural areas.⁵

For rural- and frontier-dwelling Americans who reside in a health professional shortage area, access to certain services might functionally cease to exist as a result of religious exemptions: seeking care in distant locales might be too burdensome or expensive. This holds, too, for lower income Americans who lack the financial means to seek out care for procedures when their primary physicians decline to provide services.

Racial and ethnic minority women have reported experiencing race-based discrimination when receiving family planning care.⁶ Religious exemptions may exacerbate this problem and the consequences that follow for women of color and their children.

For the LGBTQ communities, religious exemptions may further exacerbate health care access disparities. As noted above, LGBTQ Americans experience discrimination in health care settings, erecting a barrier to accessing health care services. Religious exemptions codify what many within and beyond the LGBTQ communities view as state-sanctioned discrimination, and allow providers to refuse care or appropriate referrals solely based on their patients' sexual orientation or gender identity. This stands in stark opposition to OCR's stated goal to "protect fundamental rights of nondiscrimination."

The protections provided LEP populations by notice / tagline requirements outweigh any cost savings that might be achieved.

The 2016 final rule set forth specific requirements on how to communicate with individuals with limited English proficiency (LEP), including notice and tagline requirements to alert LEP individuals of the availability of free language assistance services. The AAMC strongly believes that the proposed recommendation to repeal the non-discrimination notice and tagline requirements would impede

⁵ https://www.aamc.org/download/488276/data/aamccommentsonhhsproposedconsciencerightsrule.pdf

⁶ Thorburn S, Bogart LM. "African American women and family planning services: perceptions of discrimination," *Women Health*. 2005;42(1):23–39.

⁷ Cahill, S. "LGBT Experiences with Health Care," *Health Affairs* Vol. 36, No.4. 2017. Available from: https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2017.0277

access to critical language assistance services for millions of LEP individuals, contributing to and exacerbating existing racial and social inequities related to healthcare access and utilization.⁸

The Regulatory Impact Analysis in the final rule estimated that implementation of the notice requirements would impose \$3.6 million in costs in the first year of compliance and zero costs in the four years following implementation. The final rule also estimated that the tagline requirements would incur the same cost as the notice requirement (a total of \$7.2 million dollars). HHS contends that after independent analysis, the Department's original projection of the one-time notice and tagline costs "underestimated the actual costs associated with including nondiscrimination notices and taglines in significant communications and publications," and provides an alternative estimated burden of \$147 million to \$1.34 billion in annual costs and a cost savings projection of \$3.16 billion over five years. It is notable that HHS recognizes that "repealing the notice and taglines requirement may impose costs, such as decreasing access to, and utilization of, health care for non-English speakers by reducing their awareness of available translation services. Even so, such an impact is expected to be negligible."

The AAMC believes the Agency's cost estimations are inflated and at most add incremental burden given hospitals and healthcare facilities already print notice and tagline statements and therefore, these costs should not count toward the "recurring costs" (e.g., paper, postage) that HHS indicates the final rule failed to account for in its regulatory burden assessment. HHS' conclusions also lack sufficient evidence to justify the removal of the notice and tagline requirements, especially without proposing an alternative process that ensures meaningful access to LEP assistance.

We also strongly disagree with HHS' contention that the result of removing the notice and tagline requirements would have negligible impact on LEP populations. To illustrate the impact of these requirements, HHS relies primarily on data and anecdotal feedback from private health insurance companies. We urge HHS to engage minority health professional organizations and advocacy groups to better understand the real human and societal costs of repealing the nondiscrimination and tagline requirements. Relying primarily on cost assessments and feedback from select covered entities/stakeholders to measure the impact of the notice and tagline requirements does not provide a complete and accurate perspective on the value of the current regulations.

The AAMC appreciates the opportunity to comment on ensuring nondiscrimination in health care, and we look forward to working with the HHS on this issue. Please contact me or my colleagues Philip M.

⁸ Proposed Changes to the Health Care rights Law and Language Access, Asian & Pacific Islander American Health Forum, "25 million individuals in the U.S. are LEP, meaning they speak little to no English" (June 2019). Available from: https://www.apiahf.org/resource/proposed-changes-to-the-health-care-rights-law-and-language-access/

⁹ 84 Fed. Reg. 27858 (June 14, 2019).

¹⁰ *Id*.

¹¹ 84 Fed. Reg. 27882 (June 14, 2019).

^{12 84} Fed. Reg. 27846 (June 14, 2019), Aetna Health Plan Representatives, Member Reaction to 1557 Taglines (April 13, 2017).

¹³ 84 Fed. Reg. 27882 (June 14, 2019), "Reports from covered entities suggest, anecdotally, that utilization of translation services did not appreciably rise after the Final Rule's imposition of notice and taglines requirements." *Id*.

Alberti, PhD (palberti@aamc.org) or Ivy Baer, JD (ibaer@aamc.org) with questions about these comments.

Sincerely,

David J. Skorton, MD President and CEO

Association of American Medical Colleges

David Sustan



August 12, 2019

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#370-18

U.S. Department of Health & Human Services Office for Civil Rights Attention: Section 1557 NPRM, RIN 0945-AA11 Hubert H. Humphrey Building, Room 509F 200 Independence Ave., SW Washington, DC 20201

Submitted electronically to http://www.regulations.gov

RE: RIN 09045-AA11

Ladies and Gentlemen:

The American Federation of State, County & Municipal Employees (AFSCME) is pleased to submit comments to the U.S. Department of Health & Human Services (HHS) on the proposed rule regarding nondiscrimination in health and health education programs or activities.

AFSCME's 1.4 million members—women, men, transgender and gender nonconforming—serve in hundreds of occupations across the nation, providing the vital services that make America happen. Many AFSCME members work in our nation's health care system night and day to provide quality care for patients. In hospitals, clinics, long-term care facilities, public health, emergency services and other practice settings, we are nurses, aides, EMTs and paramedics, dietitians and food service workers, custodians, technicians, medical interpreters, physician assistants, therapists, doctors, pharmacists and administrative staff.

AFSCME advocates for fairness in the workplace, excellence in public services and freedom and opportunity for all working families. We work to promote policies that prohibit harassment, discrimination and retaliation in employment for our members, as well as policies that affirm the rights and fair treatment of the people with whom we come into contact in our work.

In the notice of proposed rulemaking, HHS seeks to cut significantly the nondiscrimination protections afforded individuals who access or seek to access health programs or activities by amending the 2016 final rule implementing the Health Care Rights Law, Section 1557 of the Affordable Care Act (ACA). Contravening the ACA's clear intent and its overriding purpose of eliminating discrimination in health care, the proposed changes risk inflicting wide-ranging harm, especially on people seeking reproductive health care, including abortion, LGBTQ individuals, individuals with limited English proficiency (LEP), individuals living with disabilities, and people of

color—many of whom already experience significant barriers to getting the care they need. Moreover, the proposed rule would embolden compounding levels of discrimination against individuals who live at the intersection of these identities. For these reasons and those stated below, we urge HHS to withdraw the proposed amendments and maintain the current Section 1557 regulation.

Who Is Covered by the Rule

HHS proposes to narrow significantly the scope of entities covered under the Section 1557 regulation. In the 2016 final rule, HHS applied the nondiscrimination requirements to 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, as well as to those of an entity engaged in the business of health care. Among other changes, HHS now proposes to exempt from application of the nondiscrimination requirements the non-HHS-funded operations of an entity principally engaged in the provision or administration of health-related services or health-related insurance coverage. For example, the nondiscrimination requirements would apply only to the individual coverage offered by an insurer in an ACA state or federal marketplace but not to other non-marketplace insurance it offers, whether it be individual or group coverage. As a result of this change and contrary to the expansive intent behind this law, many fewer individuals will be covered by Section 1557's protections, with very few people participating in employment-based group health plans covered by it.

Language Assistance

The proposed amendments would weaken the requirements and protections included in the Section 1557 rule for LEP individuals, putting at risk equal access to health care for approximately 25 million people in the U.S.¹ As has been widely established, lack of appropriate language assistance can have serious and sometimes tragic consequences. For example, previous investigations by AFSCME into the experiences of LEP patients and medical interpreters with the health care system revealed numerous examples of serious harm to patients, as well as patients' everyday struggles trying to communicate in health care settings and encountering acts of discrimination by providers.²

Language assistance is a unique health care service that is critical to ensuring nondiscriminatory care for LEP individuals. As a representative of the Joint Commission, a not-for-profit organization that accredits and certifies health care organizations and programs in the U.S., has noted:

¹ Of the 66 million individuals who speak a language other than English at home, 25 million speak English less than "very well" and therefore are considered to be LEP. U.S. Census Bureau, 2017 American Community Survey 1-Year Estimates: Table S1603 Characteristics of People by Language Spoken at Home,

https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_17_1YR_\$1603&prodType =table (last visited Jul. 17, 2019); U.S. Census Bureau, 2017 American Community Survey 1-Year Estimates: Table \$1601 Language Spoken at Home,

https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_17_1YR_S1601&prodTvpe=table (last visited Jul. 17, 2019).

² Sally Tyler, Health Policy Analyst, AFSCME to Leon Rodriguez, Dir., Office of Civil Rights, HHS, regarding RIN 0945-ZA01 (2013). *Available at*: https://www.regulations.gov/document?D=HHS-OCR-2013-0007-0113.

Today, effective communication—which takes into account language, cultural differences, and health literacy—is seen as a prerequisite to safe health care. Communication problems are the most frequent root cause of serious adverse events reported to the Joint Commission's Sentinel Event Database, and a Joint Commission study found that when patients suffer adverse outcomes from medical errors, the outcomes are more serious in [LEP] patients than in English-speaking patients. Patient rights, quality of care, and patient safety each in itself is sufficient to justify a commitment to effective communication. Together they make effective communication in health care obligatory—it is a critical component of the health care itself.³

Numerous scholarly studies support the value and importance of language assistance—especially qualified medical interpretation—to health care quality and patient outcomes. This scholarship has been evaluated by What Works for Health, a research project affiliated with the University of Wisconsin's Population Health Institute, which assesses the evidence supporting various health policies and programs. The use of trained medical interpreters to support quality of care received the project's highest possible evidence rating of "Scientifically Supported." The institute explains, "Strategies with this rating are most likely to make a difference. These strategies have been tested in many robust studies with consistently positive results."

HHS proposes replacing the two-factor test for evaluating a covered entity's compliance regarding language assistance services with a four-factor test previously provided for in HHS's 2003 LEP Guidance. Under the current-rule two-factor test, HHS (1) evaluates and gives substantial weight to the nature and importance of the health program or activity and the communication at issue and (2) takes into account other relevant factors, including whether a covered entity has developed and implemented a language access plan. Under the four-factor test, HHS would look at (1) the number and proportion of LEP individuals who are eligible or likely to be served, (2) the frequency of contact, (3) the nature and importance of the program or activity, and (4) the resources required and costs associated with providing language assistance.

The proposed approach is likely to deemphasize the needs of an individual and therefore increase the risk of harm from ineffective communication that the Health Care Rights Law and the implementing regulation were intended to address. Further, removing explicit consideration of language access plan adoption and implementation when assessing compliance likely will result in fewer covered entities preparing such plans and therefore have a negative impact on LEP individuals. The absence of a formal plan for providing language assistance is likely to result in fragmented and often informal or *ad hoc* provision of language assistance services. Busy medical providers will be tempted to use ad hoc interpreters if it is easier and faster to do so, risking real harm to patients.⁵

³ Paul M. Schyve, Language Differences as a Barrier to Quality and Safety in Health Care: the Joint Commission Perspective, 22 J. General Internal Med. 360 (citations omitted). Available at: https://link.springer.com/article/10.1007/s11606-007-0365-3.

⁴ University of Wisconsin Population Health Institute, What Works for Health, *Professionally Trained Medical Interpreters* (2017), http://whatworksforhealth.wisc.edu/program.php?t1=22&t2=17&t3=28&id=637. Evidence definitions are available at http://whatworksforhealth.wisc.edu/rating-scales.php.

⁵ See, e.g., University of Wisconsin Population Health Institute, *Professionally Trained Medical Interpreters*. ("Professional interpreters appear to make fewer clinically significant errors than ad hoc interpreters such as family, friends, or untrained staff, and lead to higher patient satisfaction.")

-4-

The proposed changes would remove video remote interpreting standards from the Section 1557 rule and require only audio remote interpreting for spoken language interpretation. In doing so, HHS does not adequately address differences in the mode of interpretation and their potential impact on the care received. For example, one scholarly study comparing in-person, video and telephonic medical interpretation found providers and interpreters were more critical of remote interpreting and had a clear preference for video over telephone. The same study also found that phone interviews were significantly shorter than in-person interviews, raising the possibility of misinterpretation in telephonic-interviews. At a minimum, the type of interpreting during a medical visit should depend on the type of encounter. Keeping the standard allows providers to determine which technology is appropriate and requires a covered entity using video to ensure that is high quality and without lagging.

The proposed rule would eliminate the requirement that covered entities provide notice of the right to language assistance and how to receive that assistance in all significant documents and notices using in-language tag lines in the top 15 languages in a state. Many people are unaware of their health care rights and how to access language assistance, making in-language notice essential, especially in documents related to their care and their access to it. This applies equally to insurance benefit documents and notices, particularly as insurers and health plans increasingly play the role of gatekeepers to care and treatment. As noted in one scholarly article,

Individuals seeking specialty care often need referrals and insurance prior authorizations, and they may subsequently need to address medical billing errors. These tasks are rarely trivial for U.S. citizens. They may be all but insurmountable for immigrations with limited literacy, English proficiency, or prior experience with comparable health systems.⁷

Sex Discrimination

Sex discrimination in health care has a disproportionate impact on women of color, LGBTQ people, and individuals living at the intersections of multiple identities—resulting in them 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 well-documented gender-based discrimination.

⁶ Craig Locatis, et al., Comparing In-Person, Video, and Telephonic Medical Interpretation, 25 J. General Internal Med. 345. Available at: https://link.springer.com/article/10.1007/s11606-009-1236-x.

⁷ Katherine Yun, et al., Help-seeking Behavior and Health Care Navigation by Bhutanese Refugees, Journal of community health, 41 J. Community Health 526 (2016). Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4842338/.

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 the 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 disproportionately impact LGBTQ people, and especially transgender, non-binary, and gender nonconforming people, who already face unique barriers to accessing care, such as high uninsurance rates, discrimination and harassment. Under the proposed rule, those barriers would only increase. For example, 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 a pap smear or mammogram. 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.

The proposed rule would disproportionately impact women and people of color who are pregnant, especially those living in rural areas. Women of color already face unique barriers to accessing pregnancy-related and abortion care, because of discrimination, harassment, and refusals of care, as well as high rates of pregnancy-related complications. For example, Asian American and Pacific Islander ("AAPI") women are two times as likely to die from pregnancy-related causes than white women, Black women are three to four times more likely to die from pregnancy related complications than white women, and Native American women were four and a half times more likely to die during or immediately after pregnancy than white women.

The proposed unlawful incorporation of Title IX's exemptions would cause further harm to LGBTQ people and women of color. 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.

Sexual Orientation and Gender Identity Protections in Unrelated Regulations

Although the 2016 final rule did not amend other HHS health care regulations, HHS is now proposing to erase all references to gender identity and sexual orientation in all HHS health care regulations, even though they are unrelated to Section 1557 and predate the 2016 final rule. 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 communities across the country.

Prior to the passage of the ACA, being transgender was treated as a pre-existing condition. As a result, transgender people could not get insurance coverage or affordable insurance. Under the proposed rule, states and Marketplaces could discriminate against LGBTQ people in eligibility determinations, enrollment periods, and more. Similarly, agents and brokers who assist with enrollment in marketplace plans could discriminate against LGBTQ people.

Prohibitions on Discrimination in Insurance Plan Benefit Design and Marketing

Before the ACA, people with serious 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, on a plan's most expensive tier, and from categorically excluding coverage for all health services related to gender transition. 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 disproportionately impact LGBTQ people and people of color who live with disabilities 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.

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.

9 Id.

⁸ MaryBeth Musumeci, et al., *HHS's Proposed Changes to Non-Discrimination Regulations under ACA Section 1557*, Kaiser Family Foundation Issue Brief (2019). Available at: http://files.kff.org/attachment/Issue-Brief-HHSs-Proposed-Changes-to-Non-Discrimination-Regulations-Under-ACA-Section-1557.

-7-

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.

For the reasons stated above, AFSCME urges HHS to withdraw the proposed rule. Please contact me with any questions you may be have regarding them.

Sincerely,

Steven Kreisberg, Director Director of Research and

Collective Bargaining services

SK:jm



Submitted electronically to http://www.regulations.gov

August 12, 2019

Secretary Alex M. Azar II
Department of Health and Human Services
Office for Civil Rights
Attn: Section 1557 NPRM (RIN 0945-AA11)
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

RE: Nondiscrimination in Health and Health Education Programs or Activities Proposed Rule

(RIN 0945-AA11)

Dear Secretary Azar:

On behalf of the American Speech-Language-Hearing Association, I write to offer comments on the Nondiscrimination in Health and Health Education Programs or Activities proposed rule.

The American Speech-Language-Hearing Association (ASHA) is the national professional, scientific, and credentialing association for 204,000 members and affiliates who are audiologists; speech-language pathologists; speech, language, and hearing scientists; audiology and speech-language pathology support personnel; and students.

ASHA appreciates the opportunity to share views on several proposed policy changes in interpreting and enforcing the nondiscrimination provision of the Affordable Care Act (ACA). Overall, ASHA supports the work of the Department of Health and Human Services ("the Department") to promote and to protect the health care rights of all Americans. ASHA recognizes that the Department underwent an extensive process to develop regulations for Section 1557, including a Request for Information, proposed rule, and final rule, considering more than 24,875 public comments received for the 2016 rule. However, ASHA is concerned that the current proposed rule unnecessarily reopens the rule and ignores the reasoned process the Department previously undertook.

Therefore, ASHA writes to express opposition to several proposals that could cause harm and roll-back protections to people based on sex, national origin, and/or disability. In this proposed rule, the Department appears to give substantial consideration to the burdens (e.g., economic, regulatory) the current regulation puts on covered entities. ASHA does not disagree that it is important to reduce these burdens, but requests that consideration also be given to the burdens (e.g., access, economic) and impacts on the health and welfare of the patients (and their family/caregivers) who are seeking services. Furthermore, ASHA recommends that the Department should 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 benefit design, coverage claims, or imposing additional costs.

This letter includes ASHA's comments on the following topics discussed in the Nondiscrimination in Health and Health Education Programs or Activities proposed rule:

- Remove Notice Requirement
- Meaningful Access for Individuals with Limited English Proficiency

- Effective Communication for Individuals with Disabilities
- Discrimination on the Basis of Sex
- Nondiscrimination in Health-Related Insurance and Other Health-Related Coverage

Remove Notice Requirement

In response to feedback from covered entities regarding increased and undue regulatory burden, the Department proposes to remove 45 CFR 92.8, which requires covered entities to provide nondiscrimination notices in English and include taglines in the top 15 languages spoken by individuals with limited English proficiency (LEP) in the state. The notices must also indicate the availability of language assistance services. While ASHA supports efforts to minimize undue financial and/or administrative burdens to audiologists and speech-language pathologists, rather than removing the requirement entirely, ASHA recommends that the Department revise this provision. Instead of requiring covered entities to include the top 15 languages spoken in the state, ASHA recommends exploring less burdensome requirements such as ensuring access to interpretation or translation services for the top 10 languages served by the covered entity. Another viable option is to revise the requirement to ensure language assistance services are based on a percentage of the LEP population.

The notice and taglines inform LEP individuals about how to access language assistance services and encourage those individuals to identify themselves and the languages in which they communicate. The benefits of improved access to and understanding of health care services for LEP individuals cannot be outweighed by cost factors alone. In addition, the Office for Civil Rights already has the responsibility of translating the sample notice, which maximizes efficiency and economies of scale and allows covered entities to receive the benefits of having multi-language notices available without incurring the associated translation costs.

Meaningful Access for Individuals with Limited English Proficiency

Currently, 45 CFR 92.201 requires covered entities to take reasonable steps to provide meaningful access to oral interpretation and/or written translation services, free of charge, to each individual with LEP who is eligible to be served or likely to be encountered. In this proposed rule, the Department proposes to relax the standards by replacing "each individual" with a general reference to "LEP individuals." If finalized, focusing on LEP individuals in general—as opposed to each individual—could result in some individuals not receiving the services they need for meaningful access. ASHA's Code of Ethics requires its members to assist clients with accessing care and ASHA maintains that providing resources to assist clients to access care is a professional responsibility.

ASHA supports maintaining the current interpretation of 45 CFR 92.201 that focuses on each LEP individual. However, instead of the Department adopting an overly prescriptive approach or standard, ASHA recommends that the Department—through sub-regulatory guidance—communicate to providers their flexibility in meeting such a requirement as long as there is documentation provided to individuals about how to acquire the needed interpreter services. Examples of such documentation include adopting more robust provider network adequacy requirements that emphasize 1) languages spoken by covered entities and 2) expanding policies that promote access to and engagement in telehealth services to minimize the linguistic challenges faced by LEP individuals.

Video Remote Interpreting Services

The Department proposes to repeal the technical and training requirements (45 CFR 92.201(f)) for the use of video remote interpreting services for LEP individuals because foreign language

speakers can, in many circumstances, rely solely on a clear audio transmission for effective communication. In addition, given that equipment and training costs for more sophisticated video remote interpreting technology can be more expensive than audio, the Department states that additional video standards may not justify the costs, particularly with respect to small providers. The current definition requires video that is high quality, real-time, full-motion, large, sharply delineated, and does not transmit blurry or grainy images.

ASHA does not support repealing the current definition of video remote interpreting services for LEP individuals. Audiologists and speech-language pathologists have expertise serving individuals who are experiencing difficulties in communicating effectively. These individuals often rely on redundancies and alternatives to compensate for any parts of communication that they may be missing. Individuals who are limited English proficient and have a communication disorder need even more information provided in as many ways as possible to allow them to receive messages completely. Nonverbal language is an important component to any language. In order to accurately diagnose social communication disorders, there needs to be assessments and interpretations of nonverbal language communication and skills. This would also apply to brain injuries, including stroke. In these situations, it is challenging for the interpreter to know what is going on in the session when they cannot see any materials/activities, and it is challenging for the client to divide attention between the tasks in person, and the language input via the phone.

Research in early language development indicates that as infants and toddlers develop language, nonverbal communication plays an important role.¹,²,³ An interpreter who cannot see what a young child is doing, cannot fully interpret what the child is communicating. This would also be the case for adults interacting through shared cues, eye contact, frequency of glances, blink rate, gestures, facial expressions, postures, etc. In addition, for individuals with any amount of attention deficit, it would be difficult to maintain focus and attention (much less process language) with only audio input. Relying solely on audio interpretation could significantly decrease the potential for individuals to express or receive messages clearly. In health care settings, this can result in compliance issues, and in LEP individuals' abilities to follow instructions, which could lead to life threatening consequences.

Effective Communication for Individuals with Disabilities

The Department seeks comment on whether to exempt entities with less than 15 employees from the requirement to provide appropriate auxiliary aids and services to people with impaired sensory, manual, or speaking skills, where necessary to afford an equal opportunity to benefit from the health program or activity, as permitted under Section 504 of the Rehabilitation Act. ASHA understands that small practice audiologists and speech-language pathologists do not have the same resources as larger practices and that exemptions—in some instances—are most appropriate. However, ASHA does not agree that there should be exemptions when it relates to effective communication. The inability to effectively communicate and miscommunications can have significant adverse effects on an individual's access to, participation in, compliance with, and decision-making in health care. The ability to effectively communicate includes the individual patient as well as the patient's family/caregivers. ASHA's Code of Ethics states that individuals shall honor their responsibility to hold paramount the welfare of persons they serve professionally and ASHA's vision is to make effective communication, a human right, accessible and achievable for all.

ASHA appreciates the consideration given to the economic burden that may be placed on small practices. However, there are programs that provide tax benefits and funding for the provision of

reasonable accommodations, which can significantly reduce burdens that covered entities may face.^{5, 6}

Discrimination on the Basis of Sex

Currently, the regulation defines sex discrimination to include discrimination on the basis of gender identity and sex stereotyping (45 CFR 92.4). The Department proposes to repeal this definition and to also eliminate the definition of gender identity, which includes gender expression and transgender status. In addition, the Department proposes to remove specific provisions that require covered entities to treat individuals consistent with their gender identity (45 CFR 92.206 and 92.207(b)(3)).

By proposing to eliminate protections against discrimination based on transgender status and sex stereotyping, the Department is contradicting over 20 years of federal case law and clear Supreme Court precedent. ⁷, As noted, ASHA opposes proposed changes to roll back other, long-standing rules that prohibit discrimination on the basis of gender identity and sexual orientation. ⁸ These changes are outside of the Office for Civil Rights' jurisdiction and are unrelated to Section 1557 of the ACA. It is not appropriate for these rulemakings to be combined nor is it appropriate the Department to characterize them as "conforming amendments" without offering any legal, policy, or cost-benefit analysis for them and its impact on various CMS programs. In particular, the Department offers no analysis of the impact these regulations have had during the years—in some cases over a decade—that they have been in effect or the impact of changing them now.

While ASHA recognizes that gender identity and gender expression are not explicitly referenced in statute, ASHA maintains that they are covered by the term sex as supported by established case law. ASHA does not support the repeal of the current definitions of sex or gender identity. In addition, ASHA opposes removal of transition-related care coverage protections or requirements for the provider to determine the individual's gender. ASHA's Code of Ethics states in part that individuals shall not discriminate in the delivery of professional services or in the conduct of research and scholarly activities on the basis of sex, gender identity/gender expression, or sexual orientation. Nondiscrimination protections must remain for these individuals as well.

Nondiscrimination in Health-Related Insurance and Other Health-Related Coverage

The current prohibition on discrimination in health-related insurance and other health-related coverage under Section 1557 (45 CFR 92.207), and particularly benefit design, is critically important for ensuring access to medically necessary and appropriate care to all individuals. These protections are especially important for people with disabilities and those with serious or chronic conditions. ASHA opposes any efforts to repeal this section of the current regulation.

Habilitative and Rehabilitative Services and Devices

Discriminatory benefit design often emerges in the area of habilitative and rehabilitative services and devices. Within this category, people with disabilities and/or chronic conditions experience discrimination on the basis of age, disability, and the type or severity of their disability.

Habilitation and Developmental Disability

Habilitation refers to services or devices that help people gain skills or functioning that they have never had. Rehabilitation refers to services or devices that help people regain skills or functioning that they have lost due to illness or injury. People with developmental disabilities are routinely denied coverage for habilitative services, such as

> speech therapy, needed to gain skills or improve functioning while an identical service is provided to individuals who would require rehabilitative care to restore functioning. ASHA is opposed to blanket service exclusions and these should be considered "unlawful on its face". The result of the proposed repeal of the health-related insurance and other health-related coverage provisions could be systematic denials of habilitation coverage for people with developmental disabilities that ASHA views as prohibited discrimination on the basis of disability (28 CFR 35 and 42 USC 18022(b)(4)(B)).

Voice Treatment

As mentioned, ASHA supports coverage protections for transgender individuals and access to gender transition. ASHA members provide vital speech-language pathology services to individuals who want to ensure their voice reflects their gender identity.¹⁰ Unfortunately, health plans inconsistently cover voice treatment for transgender individuals, even when they identify it consistently as a key health service related to their transition. 11 According to the Report of the 2015 U.S. Transgender Survey, voice treatment is the second most common reported medical intervention, behind hair removal, for transgender individuals assigned male at birth. 12 Ensuring voice treatment for all individuals in need of voice treatment—including transgender individuals—is a positive outcome.

Hearing Aids

Age limits are often applied on coverage for hearing aids. Several essential health benefit (EHB) benchmark plans offer no coverage at all or limit coverage to children only. Failure to cover hearing aids discriminates against a specific segment of people with hearing loss. In addition, coverage of hearing aids for children only and not for adults potentially violates the ACA prohibition against discrimination in plan design based on age.

ASHA does not support the Department's proposal to delete regulations that prohibit discrimination on the basis of association with a protected class (45 CFR 92.209). ASHA is particularly concerned about eliminating this right because the courts have upheld such a right for exactly the types of patients ASHA members treat. 13 Elimination of the prohibition against discrimination based on an individual's association or relationship will create uncertainty and confusion regarding the responsibilities of providers and the rights of persons who experience discrimination. Further inconsistencies with other regulatory requirements that entities are subject to, including the Americans with Disabilities Act and Section 504 of the Rehabilitation Act, would be problematic as well.

In closing, ASHA reiterates its opposition to the provisions outlined above because they are either contrary to the law or legal precedent and would have a negative impact on the ability of individuals treated by audiologists and speech-language pathologists to access medically necessary care. ASHA appreciates the opportunity to provide comments on this proposed rule. If you or your staff have any questions, please contact Daneen G. Sekoni, MHSA, ASHA's director of health care policy, health care reform, at, dsekoni@asha.org.

Sincerely,

Shari B. Robertson, PhD, CCC-SLP

Shari B. Robertson

2019 ASHA President

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¹ Rowe, M.L., Özçalişkan, Ş., & Goldin-Meadow, S. (2008). *Learning words by hand: Gesture's role in predicting vocabulary development. First Language*, 28, (2), 182- 199.

² Iverson, J. M., & Goldin-Meadow, S. (2005). *Gesture Paves the Way for Language Development. Psychological Science*, 16,(5), 367-371.

³ Goodwyn, S., Acredolo, L., & Brown, C. (2000). *Impact of symbolic gesturing on early language development. Journal of Nonverbal Behavior.* 24, 81-103.

⁴ National Archives Federal Register. (2019. Nondiscrimination in Health and Health Education Programs or Activities. Retrieved from 84 FR 27867. Retrieved from https://www.federalregister.gov/documents/2019/06/14/2019-11512/nondiscrimination-in-health-and-health-education-programs-or-activities.

⁵ U.S. Department of Justice. American with Disabilities Act Update: A Primer for Small Business. (2010). Retrieved from https://www.ada.gov/regs2010/smallbusiness/smallbusprimer2010.htm.

⁶ Internal Revenue Service. (n.d.). Form 8826, Disabled Access Credit. Retrieved from https://www.irs.gov/forms-pubs/about-form-8826.

⁷ See, e.g., Rumble v. Fairview Health Servs., No. 14–cv–2037, 2015 WL 1197415 (D. Minn. Mar. 16, 2015); Flack v. Wis. Dep't of Health Servs., No. 3:18-cv-00309-wmc (W.D. Wis. July 25, 2018); Cruz v. Zucker, 195 F.Supp.3d 554 (S.D.N.Y. 2016); Prescott v. Rady Children's Hosp.-San Diego, 265 F.Supp.3d 1090 (S.D. Cal. Sept. 27, 2017); Tovar v. Essentia Health, No. 16-cv-00100-DWF-LIB (D. Minn. September 20, 2018); Boyden v. Conlin, No. 17-cv-264-WMC, 2018 (W.D. Wis. September 18, 2018); Whitaker v. Kenosha Unified School District, No. 16-3522 (7th Cir. 2017) (Title IX and Equal Protection Clause); Dodds v. U.S. Dep't of Educ., 845 F.3d 217 (6th Cir. 2016) (Title IX and Equal Protection Clause); Barnes v. City of Cincinnati, 401 F.3d 729 (6th Cir. 2005) (Title VII of the 1964 Civil Rights Act); Smith v. City of Salem, 378 F.3d 566 (6th Cir. 2004) (Title VII); Rosa v. Park West Bank & Trust Co., 214 F.3d 213 (1st Cir. 2000) (Equal Credit Opportunity Act); Schwenk v. Hartford, 204 F.3d 1187 (9th Cir. 2000) (Gender Motivated Violence Act); Schroer v. Billington, 577 F. Supp. 2d 293 (D.D.C. 2008) (Title VII); Grimm v. Gloucester County School Board, No. 4:15-cv-54 (E.D. Va. May 22, 2018); M.A.B. v. Board of Education of Talbot County, 286 F. Supp. 3d 704 (D. Md. March 12, 2018).

⁸ Price Waterhouse v. Hopkins, 490 U.S. 228 (1989)

⁹ See, e.g., Rumble v. Fairview Health Servs., No. 14–cv–2037, 2015 WL 1197415 (D. Minn. Mar. 16, 2015) (holding that discrimination against hospital patient based on his transgender status constitutes sex discrimination under Section 1557 of the Affordable Care Act); Flack v. Wis. Dep't of Health Servs., No. 3:18-cv-00309-wmc (W.D. Wis. July 25, 2018) (holding that a Medicaid program's refusal to cover treatments related to gender transition is "text-book discrimination based on sex" in violation of the Affordable Care Act and the Equal Protection Clause of the Constitution); Cruz v. Zucker, 195 F.Supp.3d 554 (S.D.N.Y. 2016) (holding exclusion invalid under the Medicaid Act and the Affordable Care Act); Prescott v. Rady Children's Hosp.-San Diego, 265 F.Supp.3d 1090 (S.D. Cal. Sept. 27, 2017) (holding that discrimination against transgender patients violates the Affordable Care Act); Tovar v. Essentia Health, No. 16-cv-00100-DWF-LIB (D. Minn. September 20, 2018) (holding that Section 1557 of the Affordable Care Act prohibits discrimination on the basis of gender identity); Boyden v. Conlin, No. 17-cv-264-WMC, 2018 (W.D. Wis. September 18, 2018) (holding that a state employee health plan refusal to cover transition-related care constitutes sex discrimination in violation of Title VII, Section 1557 of the ACA, and the Equal Protection Clause).

¹⁰ The American Speech-Language-Hearing Association. (n.d.). Providing Transgender Voice Services. Retrieved from https://www.asha.org/practice/multicultural/Providing-Transgender-Transsexual-Voice-Services/.

 ¹¹ Tina Babajanians. (2019, February 1). Giving Voice to Gender Expression. *The ASHA Leader*). See https://leader.pubs.asha.org/doi/10.1044/leader.FTR2.24022019.54.
 ¹² National Center for Transgender Equality. (2015). *U.S. Transgender Survey*. Retrieved from

¹² National Center for Transgender Equality. (2015). *U.S. Transgender Survey*. Retrieved from http://www.transequality.org/sites/default/files/docs/usts/USTS%20Full%20Report%20-%20FINAL%201.6.17.pdf [PDF].

¹³ Falls v. Prince George's Hosp. Ctr., No. Civ. A 97–1545, 1999 WL 33485550 at * 11 (D. Md. Mar. 16, 1999) (holding that parent had an associational discrimination claim under Section 504 when hospital required hearing parent to act as interpreter for child who was deaf). Cf. Questions and Answers About the Americans with Disabilities Act's Association Provision.



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August 13, 2019

The Honorable Alex M. Azar, II Secretary U.S. Department of Health and Human Services Herbert H. Humphrey Building, Room 509F 200 Independence Avenue, SW Washington, DC 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 physician and medical student members of the American Medical Association (AMA), I am writing to express our opposition to the Notice of Proposed Rulemaking (NPRM) entitled, "Nondiscrimination in Health and Health Education Programs or Activities," published by the Office for Civil Rights (OCR) and the Centers for Medicare and Medicaid Services (CMS). Section 1557 of the Affordable Care Act (ACA) was intended to help protect people who experience significant barriers to accessing health care, including lesbian, gay, bisexual, transgender, and queer (LGBTQ) people, minorities, individuals whose primary language is not English, and those in need of reproductive health care and help provide those populations equal access to health care and health coverage. This proposal, however, is contrary to the intent and the plain language of the law. It will negatively affect patients by drastically limiting the scope of health plans to which the non-discrimination provisions apply, thereby eliminating coverage protections for certain individuals, such as transgender people, women, LGBTQ people, and individuals living with HIV. The NPRM also eliminates anti-discrimination protections based on gender identity and sex stereotypes, despite decades of case law recognizing such protections, including in the context of section 1557.

The NPRM comes on the heels of the Department of Health and Human Services' (HHS) final regulations on more than 20 federal statutory provisions related to the ability of individuals and health care institutions to refuse to provide services to which they have religious or moral objections, as well as significant revisions by HHS to the Title X program, both of which empower individuals and institutions to refuse to provide or participate in medical treatment, services, information, and referrals. Meanwhile, **this proposal marks the rare occasion in which a federal agency seeks to remove civil rights protections.** It legitimizes unequal treatment of patients by not only providers, health care organizations, and insurers, but also by the government itself—and it will harm patients. HHS states that the NPRM is necessary to "address legal concerns" raised by the *Franciscan Alliance v. Burwell* litigation and simplify regulatory confusion, but it in fact creates confusion and enables discrimination. It deems certain classes of people less worthy of care, compassion, access, and good health than others. Such policy should not be permitted by the U.S. government, let alone proposed by it.

Case 1:20-cv-05583-AKH Document 76-1 Filed 09/17/20 Page 61 of 73

The Honorable Alex M. Azar, II August 13, 2019 Page 2

Respect for the diversity of patients is a fundamental value of the medical profession. There is no basis for the denial to any human being of equal rights or privileges because of an individual's sex, sexual orientation, gender, gender identity or transgender status, race, religion, disability, ethnic origin, national origin, or age. Based on longstanding policy, the AMA strongly opposes any discrimination based on an individual's sex, sexual orientation, gender identity, race, religion, disability, ethnic origin, national origin or age and any other such policies. AMA policy also supports public and private health insurance coverage for treatment of gender dysphoria as recommended by the patient's physician.

The AMA believes in the critical importance of ensuring health equity—optimal health for all—recognizing the importance and urgency of ensuring that all people and communities reach their full health potential. Unfortunately, at the provider and institutional levels, there is a growing body of evidence demonstrating that implicit and explicit biases negatively impact the quality of health care equity and patient safety and drive these inequities. Indeed, "racism is considered a fundamental cause of adverse health outcomes for racial/ethnic minorities and racial/ethnic inequities in health." Additionally, there is evidence that experiences of discrimination and racism have a "weathering" physiological effect on the body (e.g., irregular heartbeat, anxiety, heartburn), which over time can be compounded and lead to long-term negative health outcomes. The Joint Center for Political and Economic Studies estimates that health inequalities and premature deaths cost the U.S. economy \$309.3 billion a year; the proposed elimination of most of the anti-discrimination protections in the 2016 implementing regulations (Current Rule) will likely increase this figure.

As advocates for our patients, we strongly support patients' access to comprehensive health care services. Physicians are expected to provide care in emergencies, respect basic civil liberties, and not discriminate against individuals in deciding whether to enter into a professional relationship with a new patient. We expect the same for the rest of the health care system and for the federal government's health care activities and programs. In sum, the AMA strongly opposes the proposed elimination or rollback of critical protections guaranteed by section 1557 of the ACA and the Current Rule and, accordingly, we urge HHS to withdraw this proposal.

Scope of Application

Section 1557 of the ACA prohibits discrimination by "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 [Title I of the ACA]." Accordingly, under the Current Rule, an insurer that offers a plan in the ACA Marketplace must ensure that all of its plans—not only those offered in the Marketplace—comply with section 1557. However, the proposed rule improperly attempts to narrow the application of section 1557's protections

¹ David R.William et al., *Racism and Health: Evidence and Needed Research*, Annu. Rev. Public Health (Jan. 2, 2019), available at https://www.annualreviews.org/doi/pdf/10.1146/annurev-publhealth-040218-043750.

² Arline T. Geronimus, ScD, et al., "Weathering" and Age Patterns of Allostatic Load Scores Among Blacks and Whites in the United States, Am J Public Health (May 2006), available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1470581/.

³ Healthy People 2020, citing Pascoe EA, Smart RL, *Perceived discrimination and health: a meta-analytic review*, Psychol Bull. 2009;135(4):531–54, available at https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-health/interventions-resources/discrimination#5.

⁴ Thomas A. LaVeist, et al., *The Economic Burden Of Health Inequalities in the United States*, Joint Ctr. for Pol. and Econ. Stud., available at

 $[\]underline{https://jointcenter.org/sites/default/files/Economic \%20Burden \%20of \%20 Health \%20 Inequalities \%20 Fact \%20 Sheet.pdf.}$

⁵ 42 U.S.C. § 18116(a).

Case 1:20-cv-05583-AKH Document 76-1 Filed 09/17/20 Page 62 of 73

The Honorable Alex M. Azar, II August 13, 2019 Page 3

to only the portion of a health care program or activity that receives federal financial assistance. As such, insurers offering plans in the Marketplace will only need to ensure that Marketplace plans comply with section 1557—not all of their plans. **The statute is clear that it applies to health programs or activities,** *any part of which* receives federal financial assistance. If Congress had intended that only the product receiving such assistance was bound by the nondiscrimination provisions, it could have easily stated as much in very simple terms.

Additionally, the NPRM restricts the scope of application to health plans that are "principally engaged in the business of providing health care" as opposed to those primarily engaged in providing health insurance. As stated in the preamble, these criteria would thus exclude short term limited duration insurance (STLDI) plans from needing to comply with section 1557 as such plans are neither (1) principally engaged in the business of health care, nor (2) receiving federal financial assistance with respect to STLDI plans specifically. Notably, such plans are widely-regarded as discriminatory on the basis of sex, age, and disability. For example, a 2018 study found that no short term plans covered maternity care. Other data demonstrates that short term health plans charge women higher premiums than men. Free of a requirement to comply with non-discrimination laws, STLDI plans will be emboldened to deny coverage for any number of conditions and services, including those that affect only women (e.g., uterine cancer or abortion) or transgender populations (e.g., gender dysphoria or transition-related services).

HHS also appears to be narrowing the scope of the regulations to only HHS-administered health programs and activities that fall under Title I of the ACA. This is a drastic and improper shift that will have a wideranging impact, as health programs and activities such as those administered by the Health Resource Services Administration (HRSA), Centers for Disease Control and Prevention (CDC), Food and Drug Administration (FDA), Substance Abuse and Mental Health Services Administration (SAMHSA), CMS, and the Indian Health Service (IHS) would no longer be covered by section 1557. We are unsure why HHS is proposing this change as section 1557's statutory text clearly states that it applies to "any program or activity that is administered by an Executive Agency."

Each of these proposals are contrary to what section 1557's statutory text states and are a clear attempt to reduce the number of health insurance plans, health programs, and health activities covered by the regulations. This policy is not only illogical and confusing, but also creates a standard that discrimination is acceptable for some beneficiaries but not others. HHS should not finalize the proposed change in scope and should instead retain the Current Rule's application of section 1557, which accurately reflects the language and intent of the underlying statute.⁸

Protections on the Basis of Sex

The NPRM eliminates the regulatory definition of sex-based discrimination. If finalized, this will impact protections not only for LGBTQ individuals, but also for women who are pregnant, have miscarried, who have had complications with childbirth, or who have terminated a pregnancy. Loss of protections for these classes of individuals will lead to barriers to care, lack of health insurance coverage, and higher

⁶ Karen Pollitz et al., *Understanding Short-Term Limited Duration Health Insurance*, Kaiser Family Foundation (Apr. 23, 2018), available at https://www.kff.org/health-reform/issue-brief/understanding-short-term-limited-duration-health-insurance/.

⁷ Sarah Lueck, *Key Flaws of Short-Term Health Plans Pose Risks to Consumers*, Ctr. on Budget & Pol'y Priorities (Sept. 20, 2018), available at https://www.cbpp.org/research/health/key-flaws-of-short-term-health-plans-pose-risks-to-consumers.

^{8 45} CFR §92.2(a).

The Honorable Alex M. Azar, II August 13, 2019 Page 4

costs (either in premiums or cost-sharing rates) for those services that are covered. It also simply chips away at people's dignity.

The AMA strongly believes that discrimination on the basis of sex includes discrimination on the basis of gender identity and sexual orientation. The courts and federal agencies agree. Since 2012, OCR has interpreted section 1557 of the ACA's sex discrimination prohibition to extend to claims of discrimination based on gender identity or sex stereotypes and accepted such complaints for investigation. Numerous federal agencies, including the U.S. Department of Justice, U.S. Department of Labor, U.S. Department of Education, and the U.S. Department of Housing and Urban Development, have previously interpreted sex discrimination to include discrimination on the basis of gender identity. The NPRM disregards these interpretations—reversing OCR's own long-standing policy—and disregards the Supreme Court's holding in *Price Waterhouse v. Hopkins* (1989), which states that discrimination based on stereotypical notions of appropriate behavior, appearance, or mannerisms for each gender constitutes sex discrimination. Lower courts, including in the context of section 1557, have also recognized that sex discrimination includes discrimination based on gender identity.¹⁰

Section 1557's protections against sex discrimination are necessary. Transgender, nonbinary, 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, and 23 percent did not seek health care when they needed it due to fear of being disrespected or mistreated as a transgender person. 11 These rates tend to be higher for non-white respondents and individuals with disabilities. ¹² Following an early 2017 Freedom of Information Act (FOIA) request to HHS for complaints of discrimination under section 1557, the Center for American Progress (CAP) found that the most common complaints involved individuals being denied care or insurance coverage because of their gender identity or transgender status. ¹³ Examples include a transgender woman being denied a mammogram, a transgender man being refused a screening for a urinary tract infection, an insurer not covering reproductive health care because of an individual's gender identity, and an insurer not covering genetic testing for breast cancer for a transgender man despite the testing being recommended by the complainant's physician. ¹⁴ CAP notes that existing enforcement of section 1557 is "working well to resolve very real issues of discrimination, and that the fears raised by the Franciscan Alliance [v. Burwell] lawsuit are not well-founded."15 Incidentally,

^{9 490} U.S. 228 (1989).

¹⁰ See, e.g., Rumble v. Fairview Heath Servs., Civ. No. 14-cv-2037, 2015 WL 1197415 (D. Minn, Mar. 16, 2015) (Section 1557) (order denying motion to dismiss); Barnes v. City of Cincinnati, 401 F.3d 729, 737 (6th Cir.), cert. denied, 546 U.S. 1003 (2005)(Title VII); Smith v. City of Salem, Ohio, 378 F.3d 566, 575 (6th Cir. 2004) (Title VII); Schroer v. Billington, 577 F.Supp.2d 293, 304 (D.D.C. 2008) (Title VII).

¹¹ S.E. James, et al., Nat'l Ctr. for Transgender Equality, Report Of The 2015 U.S. Transgender Survey (2016), available at https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf.

¹² S.E. James, et al., Nat'l Ctr. for Transgender Equality, Report Of The 2015 U.S. Transgender Survey (2016), available at https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf.

¹³ Sharita Gruberg and Frank J. Bewkes, *The ACA's LGBTQ Nondiscrimination Regulations Prove Crucial*, Center for American Progress (March 7, 2018), available at https://www.americanprogress.org/issues/lgbt/reports/2018/03/07/447414/acas-lgbtqnondiscrimination-regulations-prove-crucial/.

¹⁴ Sharita Gruberg and Frank J. Bewkes, The ACA's LGBTO Nondiscrimination Regulations Prove Crucial, Center for American Progress (March 7, 2018), available at https://www.americanprogress.org/issues/lgbt/reports/2018/03/07/447414/acas-lgbtqnondiscrimination-regulations-prove-crucial/.

¹⁵ Sharita Gruberg and Frank J. Bewkes, *The ACA's LGBTQ Nondiscrimination Regulations Prove Crucial*, Center for American Progress (March 7, 2018), available at https://www.americanprogress.org/issues/lgbt/reports/2018/03/07/447414/acas-lgbtqnondiscrimination-regulations-prove-crucial/.

The Honorable Alex M. Azar, II August 13, 2019 Page 5

none of the complaints involved HHS ordering a health care professional to perform a service against his or her medical judgement.

Additionally, the AMA does not condone discrimination based on whether a woman has had an abortion. While the NPRM notes that Title IX prohibits discrimination based on pregnancy, including termination of pregnancy, it fails to clarify whether HHS will enforce those protections. HHS should clearly state, for example, that it is illegal for a pharmacist to refuse medication for someone who is miscarrying, or for an insurer to refuse coverage to a woman who has had an abortion. Given HHS' recent regulations finalizing the ability of individuals and health care institutions to refuse to provide services to which they morally object, as well as the significant revisions to the Title X program, protections against discrimination on the basis of pregnancy (including termination thereof) are critical. We anticipate that many women will experience barriers when they seek reproductive health services or attempt to obtain insurance coverage for reproductive health care.

Furthermore, the NPRM attempts to incorporate Title IX's religious exemption, which could permit health care entities controlled by a religious organization to discriminate if the entity claims that compliance with sex discrimination protections would conflict with its religious beliefs. If finalized, this could impact a broad range of health care services, including access to birth control, sterilization, certain fertility treatments, abortion, gender-affirming care, and end of life care. For example, religiously-affiliated pharmacies could refuse to prescribe contraception to someone because they are not married or refuse to provide infertility treatment to a same-sex or transgender couple.

Finally, HHS is proposing to eliminate prohibitions on discrimination based on gender identity and sexual orientation in 10 regulations outside of section 1557, including those concerning qualified health plan issuers, agents, and brokers that assist with Marketplace applications and enrollment; marketing or benefit design practices of health insurance issuers under the ACA; organizations operating Programs for Allinclusive Care of the Elderly (PACE) programs and participants receiving PACE services under Medicare; Medicaid beneficiary enrollment; and promotion and delivery of access and services. The regulations for these programs are not connected to section 1557 and many have been in effect for years; changing them now would not only create significant confusion, but also have wide-ranging consequences for millions of individuals. Furthermore, this NPRM is not the appropriate mechanism to revise such regulations. HHS should not finalize this proposal.

Language Access

The AMA supports access to quality care for all individuals and encourages physicians to make their offices accessible to patients with disabilities and limited English proficiency (LEP). Moreover, the AMA strongly believes that clear, direct communication and understanding is the bedrock of the patient-physician relationship and is very important in ensuring the provision of quality medical care to all patients. However, we believe that the financial burden of medical interpretive services and translation should not fall entirely on physician practices. Rather, as with interpreters or other auxiliary aids or services for individuals with hearing impairments, language interpretive services should be a covered benefit for all health plans, which are in a much better position to pass on the costs of these federally mandated services as a business expense.

Relatedly, AMA members have reported to the AMA that individuals with LEP often bring trusted adults with them to an appointment to facilitate communication. The Current Rule states that a physician may

The Honorable Alex M. Azar, II August 13, 2019 Page 6

rely on an adult accompanying an individual with LEP to interpret or facilitate communication only if reliance on that adult for such assistance is "appropriate under the circumstances." This standard remains unclear to physicians, causing them to take on the additional burden and expense of interpreters out of an abundance of caution when it may not be always necessary to do so. For example, when a physician sees an adult male patient presenting with flu-like symptoms, who is accompanied by his adult brother, and the patient requests that his brother translate, a physician may find this request appropriate under the circumstances. Conversely, if a female patient presenting with a broken arm is accompanied by her husband, the physician may have concerns about domestic abuse. In this case, it may be inappropriate to rely on the husband to provide accurate interpretation services. The AMA urges HHS to clarify the circumstances in which a physician may rely on an adult accompanying a patient to interpret or facilitate communication. We would welcome the opportunity to assist the agency with guidance.

Conclusion

This NPRM is at odds with section 1557's clear mandate. Undoing the protections of the Current Rule will cause confusion about what the law requires and who is protected by it and, in doing so, will limit access to critically needed care and services for millions of individuals. The proposed rule disproportionately harms people seeking reproductive health care (including abortion), LGBTQ individuals, individuals with LEP (including immigrants), those living with disabilities, and people of color. For the reasons detailed above, **HHS should not finalize the proposed rule, but rather should redirect their efforts toward advancing health care access and equity for all. The AMA remains ready to assist with such efforts.**

Thank you again for the opportunity to submit comments on the proposed rule. Should you have any questions or wish to discuss these issues, please contact Laura Hoffman, Assistant Director of Federal Affairs, at laura.hoffman@ama-assn.org or 202-789-7414.

Sincerely,

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James L. Madara, MD



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August 9, 2019

Secretary Alex Azar
U.S. Department of Health and Human Services
Attention: Section 1557 NPRM, RIN 0945-AA11
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue SW
Washington DC 20201

RE: Nondiscrimination in Health and Health Education Programs or Activities – Docket No.: HHS-OCR-2019-0007

Dear Secretary Azar,

On behalf of the American Psychiatric Association (APA), a national medical specialty society representing more than 38,500 physicians specializing in psychiatry, we are writing in response to the Department of Health and Human Services' (HHS or the Agency) proposed rule, *Nondiscrimination in Health and Health Education Programs or Activities*¹, as published in the Federal Register on June 14, 2019. We appreciate the opportunity to comment on this important proposal and focus our comments on the potential negative impacts it may have on health outcomes and patients' mental health.

Background

Franciscan Alliance v. Azar enjoined the implementation of a regulation that would define "on the basis of sex" to include gender identity and termination of pregnancy. The court then granted HHS a remand and stay in order to allow the Agency to correct the problem the court identified. ² In the proposed rule, HHS deleted the definition of "on the basis of sex," which had included gender identity and termination of pregnancy and altered the definition of covered entities. As a result, the proposed rule will now encourage discrimination in all facets of health care against gender diverse people and women.

The Agency and this Administration do not intend that health care providers should have carte blanche to engage in rank discrimination against entire classes of people

¹ Notice of Proposed Rulemaking, "Nondiscrimination in Health and Health Education Programs or Activities," Federal Register, Vol. 84, No. 115, Friday, June 14, 2019, pgs. 27846-27895.

² The issues of whether discrimination "on the basis of sex" includes gender identity and sexual orientation is currently under consideration by the United States Supreme Court in the combined cases *Altitude Express Inc. v. Zarda, Bostock v. Clayton County, GA*, and *R.G. & G.R. Harris Funeral Homes Inc V EEOC*. These cases will consider the issue in the context of Title VII.

with whom they disagree under the cloak of religious freedom. The plaintiffs in Franciscan Alliance made it clear that the religious objection was to providing the service or procedure that is in contrast to their religious beliefs, and not to the patient as a person. Thus, plaintiffs challenging provision of gender transition and abortion services recognized the obligation to treat transgender individuals and women who had terminated a pregnancy for "health issues ranging from the common cold to cancer," but stopped short of providing transition related services and abortions. This limit on the claim to religious or conscious objection is a basic and well-understood tenant of our law:

- HHS explicitly recognized a concern "that the proposed regulation could serve as a pretext for health care workers to claim religious beliefs or moral objections.... in order to discriminate against certain classes of patients, including illegal immigrants, drug and alcohol users, patients with disabilities or patients with HIV, or on the basis of race or sexual preference." 73 Fed. Reg. at 78,079 -80 (2008). It clarified that the regulation was not intended to permit unlawful discrimination on any basis, for "the health care provider conscience protection provisions have existed in law for many years, and this regulation only implements these existing requirements. As a result, there is nothing in this regulation that newly permits" discrimination against categories of individuals based on their individual characteristics for any reason (including, e.g., on the basis of race, color, national origin, disability, age, sex, religion, or sexual preference). 73 Fed. Reg. at 78,080 (2008).
- In 2011, an HHS action rescinded much of the 2008 Federal Health Care Conscience Rule, at least in part, as a response to litigation that was filed contesting it. The 2011 issuance made clear that the "conscience statutes were intended to protect health care providers from being forced to participate in *medical procedures* that violated their moral and religious beliefs. They were never intended to allow providers to refuse to provide medical care to an individual because the individual engaged in behavior the health care provider found objectionable." 76 Fed. Reg. at 9,973-74 (emphasis added).

Because the proposed rule does not clarify the limitation of the religious and conscience objection to providing the *procedure or service* related to abortion, gender identity or sexual orientation, it may empower providers to refuse <u>any</u> health care service or information to entire classes of people even if the health care sought is unrelated to the religiously objectionable procedure. By eliminating the definitions of terms such as "on the basis of sex" and changing the definition of "covered entity," without making it clear that discrimination against entire classes of individuals for all health services is unlawful, this rule opens to the door to discrimination against vulnerable Lesbian, Gay, Bisexual, Transgender, and Queer (LGBTQ) and female patients, placing them at-risk of serious or life-threatening results in emergency situations. The Agency cannot mean that people who have had abortions or who are LGBTQ should be lawfully denied access to treatment for cancer, heart disease or mental illness because someone with a religious belief does not think they are worthy of basic health care. Health care providers need clear instruction on what is and is not a permissible refusal to treat a patient under the guise of religious freedom.

Impact on Gender Diverse Patients

As written, the proposed rule would roll back the current definition of sex discrimination, that includes gender identity and sex stereotyping. This policy change would allow providers to refuse to treat LBGTQ patients, further endangering access to care for an already-vulnerable patient population. Additionally, if

implemented, the proposed rule would allow covered entities, such as insurers, to deny, limit, and impose additional cost-sharing for gender-specific services (such as cervical cancer screenings for women) or services related to gender transition (such as hormone therapy, mental health counseling, and surgeries) that a transgender patient may seek. As physician experts, we know that appropriately evaluated transgender and gender diverse individuals can benefit greatly from medical and surgical gender-affirming treatments.³ It is our official policy to oppose categorical exclusions of coverage for such medically necessary treatment when prescribed by a physician.

We are especially concerned about the rule's potential to exacerbate health disparities among LGBTQ patients. There is ample evidence that patients in protected classes (e.g. LGBTQ patients) are already hesitant to seek medical and mental health care and that discriminatory policies have detrimental mental health and medical impacts on the population subject to discrimination.⁴ Despite the need for health services, half of gender minorities educate their own providers about necessary care and 20 percent report being denied care. 5,6 The literature on the "minority stress model" highlights the impact of social prejudice, isolation and invisibility as the primary factors leading to an increased health burden and greater risk of mental health issues, homelessness and unemployment. Research shows that LGBTQ patients have many of the same health concerns as the general population, but they experience some health challenges at higher rates, and face several unique health challenges shaped by a host of social, economic, and structural factors. LGBTQ individuals are two and a half times more likely to experience depression, anxiety, and substance misuse. These patients also experience higher rates of sexual and physical violence against them as compared to their heterosexual counterparts. 8 Like other minority groups, transgender individuals are more likely to experience prejudice and discrimination in multiple areas of their lives (e.g., employment, housing, school, healthcare), which exacerbate these negative health outcomes and makes access to appropriate medical care all the more important. Due to their limited access to care, transgender patients have significantly increased rates of mental disorders, substance use, and suicide, 9 while the risk of physical conditions is also intensified with increased rates of

³ American Psychiatric Association. Position Statement on Access to Care for Transgender and Gender Diverse Individuals (2018). https://www.psychiatry.org/File%20Library/About-APA/Organization-Documents-Policies/Policies/Position-2018-Access-to-Care-for-Transgender-and-Gender-Diverse-Individuals.pdf

⁴ Hatzenbuehler ML, McLaughlin KA, Keyes KM, Hasin DS. 2010. The impact of institutional discrimination on psychiatric disorders in lesbian, gay, and bisexual populations: a prospective study. Am J Public Health. 100(3): 452-459.

⁵ Grant JM, Lisa A, Mottet Justin, Tanis Jack, Harrison Jody, Herman L, Keisling Mara. Injustice at every turn: A report of the National Transgender Discrimination Survey. Washington, DC; National Center for Transgender Equality and National Gay and Lesbian Task Force; 2011.

⁶ Sandy James et al., 2015 U.S. Transgender Survey 11, 12, 14 (2016),

http://www.transequality.org/sites/default/files/docs/USTS-Full-Report- FINAL.PDF

⁷ Ilan Meyer. "Prejudice, Social Stress, and Mental Health in Lesbian, Gay, and Bisexual Populations: Conceptual Issues and Research Evidence" Psychological Bulletin. 2003 Sep; 129(5): 674–697.

⁸ Jen Kates et al., "Health and Access to Care and Coverage for Lesbian, Gay, Bisexual, and Transgender Individuals in the U.S." August 2017.

⁹ Agnes Gereben Schaefer et al., Assessing the Implications of Allowing Transgender Personnel to Serve Openly, RAND Corporation (2016).

tobacco use, HIV and AIDS, and weight problems.¹⁰ We urge the Administration to remove barriers to care and support evidence-based coverage for medical care, which would help the mental well-being of gender diverse individuals.

Impact on Women's Access to Care

The proposed rule would expand abortion exemptions by incorporating blanket exemptions from Title IX and including intentionally broad language to incorporate future abortion exemptions. While the existing regulation already includes exemptions derived from federal statutory protections for religious freedom and conscience, broadening the language to include exemptions beyond abortion services could have a dangerous effect on women's access to care. In essence, this language would allow a provider to turn away a patient from any health service if they previously sought an abortion, simply because having an abortion violates the provider's religious beliefs. As the U.S. continues to see rising maternal mortality rates, 11 enabling providers to turn patients away could worsen health outcomes for women and lead to higher health costs. In rural communities, where women experience poorer health outcomes and have even more limited access to health care, 12 these expanded exemptions could be particularly devastating. APA opposes governmental restrictions on family planning and abortion services 13 and as such, recommends that the Administration not expand abortion exemptions.

Broader Implications for Health Costs and Mental Health

As the frontline physicians providing treatment for mental illness and substance use disorders, our goal is to ensure that all patients have access to effective treatment and receive care that is compassionate to their individual needs. According to the most recent National Surveyon Drug Use and Health, 80.7 percent of people aged 12 or older who needed substance use treatmentat a specialty facility did not receive it. In addition, 57.4 percent of adults with any mental illness did not receive mental health care. ¹⁴ The indirect cost of untreated mental illness to employers is estimated to be as high as \$100 billion a year in the U.S. alone. ¹⁵ Ethnic/racial minorities often bear a disproportionately high burden of disability resulting from mental disorders. Lack of cultural understanding by health care providers may contribute to underdiagnosis and/or misdiagnosis of mental illness with language differences between patient and

¹⁰ Sari Reisner et al., Global Health Burden and Needs of Transgender Populations: A Review. The Lancet, 388, 412-436

¹¹ MacDorman, M., Declercq, E., Cabral, H., Morton, C., "Is the United States Maternal Mortality Rate Increasing? Disentangling trends from measurement issues: Short title: U.S. Maternal Mortality Trends." Obstet Gynecol. 2016 Sep; 128(3):447-55.

¹² American College of Obstetricians and Gynecologists. "Health Disparities in Rural Women" (2014). https://www.acog.org/-/media/Committee-Opinions/Committee-on-Health-Care-for-Underserved-Women/co586.pdf?dmc=1&ts=20190730T0304131196

¹³ American Psychiatric Association. Position Statement on Abortion (2018). https://www.psychiatry.org/File%20Library/About-APA/Organization-Documents-Policies/Policies/Position-2018-Abortion.pdf

¹⁴ Center for Behavioral Health Statistics and Quality. (2018). 2017 National Survey on Drug Use and Health: Detailed Tables. Substance Abuse and Mental Health Services Administration, Rockville, MD.

¹⁵ Finch, R. A. & Phillips, K. (2005). An employer's guide to behavioral health services. Washington, DC: National Business Group on Health/Center for Prevention and Health Services. Available from: www.businessgrouphealth.org/publications/index.cfm

provider being a contributing factor. Lack of coverage, limited access to culturally competent providers, distrust in the health care system, and stigma are additional main barriers to accessing effective care for diverse populations.

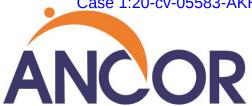
For this reason, we oppose the Agency's proposal to eliminate requirements for covered entities to provide non-discrimination notices and grievances procedures. In addition, we oppose the proposal to eliminate the standards ensuring access to language assistance services, including oral interpretation and written translation, for individuals with limited English proficiency. As an organization, we train physicians to deliver culturally competent care to serve the needs of evolving, diverse, underrepresented patient populations. Clear communication is essential to delivering quality care and these provisions would undermine necessary efforts to reduce disparities in mental health care.

A rule that would allow health care workers to deny any health care services to transgender individuals or women who have terminated a pregnancy and scales back patient protections for underserved patients will only exacerbate existing problems of access. While the proposal boasts cost savings, the proposed rule will result in higher health care costs and mortality rates, a less productive workforce, and an increased need for already scarce mental health and substance use services. It is important for us to work together to address these challenges to reduce the burden of mental health and substance use issues on patients, their families, communities, and the government. Religious freedoms can be respected without jeopardizing the basic health needs of a substantial portion of the population. We must also ensure that we do not exacerbate the need for services by adding barriers, such as discrimination or fear of discrimination against people in need of treatment. Thus, we strongly urge the Administration to rescind this proposed rule to ensure that all patients have access to care without fear of discrimination.

Thank you for the opportunity to offer our expertise. If you have any questions, please contact Kathy Orellana, Associate Director of Practice Management Policy, at korellana@psych.org or at 202-559-3911.

Soul Levin, ma, men

Saul Levin, MD, MPA, FRCP-E CEO and Medical Director



August 9, 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 these comments on behalf of the American Network of Community Options and Resources (ANCOR) in response to the Notice of Proposed Rulemaking on Section 1557 of the Affordable Case Act (ACA). ANCOR is a national trade association representing over 1,600 private providers of community services for people with intellectual and developmental disabilities (I/DD) and 57 state provider trade associations. Our members provide services to people with I/DD throughout the lifespan in all areas of life and thus changes in Section 1557 impact our service delivery in a multitude of ways.

We appreciate this opportunity to share our views on these proposed policy changes in interpreting and enforcing the nondiscrimination provision of the Affordable Care Act (ACA). We write to express concern regarding the U.S. Department of Health and Human Services (HHS) proposed rule on Section 1557. The proposed rule could cause major harm to people with disabilities and their families and communities.

Section 1557 and its implementing rules are critical because people with disabilities have historically faced discrimination in the provision of health care. Community and private providers of disability services formed to address the history of discrimination and ensure that people with I/DD had access to the same health quality outcomes as non-disabled populations. We are aware that 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. Therefore, proposed changes should be considered very carefully in light of the already significant public input.

We request that HHS retain 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. People with disabilities should have access to coverage for services including autism therapies or durable medical equipment – these are essential for high quality health outcomes.

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 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.

HHS should 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.

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. The individuals that ANCOR members work with often have significant disabilities, may be nonverbal, and require effective communicative devices to communicate. It is essential that this access is protected to ensure they can be active in decision making for their health and to reach the best outcomes.

The current Sec. 1557 final rule was the subject of a lengthy development process that included substantial public input and comment. Revisiting all of the previously settled issues in the final rule, particularly those far beyond the justification offered in the NPRM, creates uncertainly and further weakens finality. We thank you for considering our comments on this proposed rule and are happy to be a resource on any of the above mentioned issues if it serves to be of assistance.

Sincerely,

Esmé Grant Grewal, Esq. Vice President, Government Relations ANCOR M: 202-579-7789 egrewal@ancor.org