August 9, 2019

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-OCR-2019-0007; RIN 0945-AA1; Comments in Response to Proposed Rulemaking: Nondiscrimination in Health and Health Education Programs or Activities

To Whom It May Concern:

Trust for America’s Health (TFAH) is grateful for the opportunity to comment on the Department of Health and Human Services’ (HHS) proposed rule on “Nondiscrimination in Health and Health Education Programs or Activities,” which would substantially change current requirements under Section 1557 of the Patient Protection and Affordable Care Act (ACA). TFAH is a nonprofit, non-partisan organization that promotes optimal health for every person and community and makes the prevention of illness and injury a national priority. To maintain an independent voice, TFAH does not accept any government or industry funds.

Specifically, TFAH is concerned that HHS’s proposal to limit the authority and scope of Section 1557’s anti-discrimination protections would exacerbate individual- and population-level health disparities for women, LGBTQ+ individuals, people with disabilities and people with limited English proficiency (LEP). People in rural and frontier areas in particular face a number of barriers to care based on lack of providers, facilities, and other issues, and we fear the rule will worsen these disparities by placing additional barriers to accessing treatment. TFAH is also concerned about the impact these changes would have on the activities of health departments and public health agencies, including disease surveillance, vaccination, and programming. We urge HHS to reject these proposed changes and maintain Section 1557’s current authority and scope.

Background

Section 1557 of the ACA, also known as the Health Care Rights Law (HCRL), prohibits “covered entities” from discriminating against historically marginalized communities. Section 1557 also incorporates protections from existing civil rights laws (Title VI of the Civil Rights

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1 Department of Health and Human Services, “Nondiscrimination in Health and Health Education Programs or Activities” (Jun 14, 2019). Available at https://www.federalregister.gov/documents/2019/06/14/2019-11512/nondiscrimination-in-health-and-health-education-programs-or-activities


Act of 1964; Title IX of the Education Amendments of 1972; Age Discrimination Act of 1975; Section 504 of the Rehabilitation Act of 1973) and extends these protections to the provision of health care.

Under current regulations promulgated in 2016, the definition of covered entities includes:

- health care providers, such as physicians’ practices;
- hospitals, nursing homes, and organ procurement centers that receive federal funds such as Medicare (excluding Part B) or Medicaid payments;
- health-related education and research program;
- state Medicaid, Children’s Health Insurance Program (CHIP), and public health agencies;
- health insurance issuers and third-party administrators;
- state and local health departments that receive federal funding;
- state-based Marketplaces; and
- health programs administered by HHS.

The proposed rule would limit the applicability of Section 1557 to fewer entities. For instance, health related agencies under HHS, including the Centers for Disease Control and Prevention (CDC) and the Substance Abuse and Mental Health Services Administration (SAMHSA) would not be required to follow 1557 non-discrimination regulations under the new rule. Additionally, the proposed regulations would limit 1557 protections to only certain health programs and activities financed by federal funds, rather than to whole entities.

As a result of this and other changes included in the proposed rule, HHS’s own estimates project that roughly half of the current 137,501 covered entities would no longer be covered by the nondiscrimination policies in Section 1557. TFAH believes that reducing the scope of 1557 protections will lead to increased cases of discrimination or discriminatory practices in health care systems and negatively affect the aforementioned communities’ ability to access timely and necessary health care and services.

Effects on Women

Section 1557 currently prohibits discrimination on the basis of sex, defined to include discrimination related to pregnancy status and care; childbirth and related medical conditions; sex stereotyping; and gender identity. The proposed rule would repeal these subdefinitions, allow for religious exemptions to the sex discrimination provision, and include exemptions for discrimination related to pregnancy termination.

Under the proposed rule, any religiously-affiliated health care entity, including hospitals and issuers, would be exempt from complying with Section 1557 protections. As a result of this blanket exemption, women could increasingly be denied care due to hospitals’ and providers’ religious beliefs. Under this proposed change, religiously-affiliated providers could refuse to treat a woman experiencing complications related to miscarriage or pregnancy termination.

6 81 Fed Reg at 27857. .
7 81 Fed Reg at 27864. .
Patients who are unable to choose among multiple providers, including those living in underserved rural areas, may be denied services at the only hospital to which they have access.

The anticipated effects of these changes are particularly concerning given the current maternal mortality crisis in the U.S. While maternal mortality rates in other developed countries have steadily decreased, deaths from pregnancy and childbirth-related causes have steadily increased in the U.S. The United States has the highest maternal mortality rate of all OECD countries, with an average of 13.1 pregnancy or childbirth-related deaths per 100,000 live births. This number is much higher for black women, who die from pregnancy or childbirth-related causes at three times the rate of non-Hispanic, white women.

While the causes of the U.S.’s high maternal mortality rate require further research, available data suggest that high rates of chronic health conditions and insufficient health care access throughout their life course are partially to blame. It is imperative that women are able to access health services throughout their lives, regardless of their health care choices. TFAH supports efforts to break down barriers that prevent women from accessing care, and strongly opposes this proposed rule, which would create additional hurdles.

**Effects on LGBTQ+ Individuals**

In a national survey of LGBTQ+ individuals, 56 percent of lesbian, gay or bisexual respondents and 70 percent of transgender and gender non-conforming respondents said they have faced discrimination from health care providers as a result of their sexual orientation or gender identity. Of the estimated 1.4 million transgender people living in the U.S., 29 percent have

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been denied services because of their actual or perceived gender identity.\textsuperscript{20} Across the board, LGBTQ+ people of color are more likely to report experiencing discriminatory or substandard care.\textsuperscript{21,22} Importantly, perceived discrimination from health care providers can cause LGBTQ+ individuals to avoid seeking health care, which contributes to negative health behaviors and outcomes, including depression and anxiety, increased risk of non-detection of breast and cervical cancers, and higher rates of smoking and illicit drug use.\textsuperscript{23,24} Delaying care can also result in the need for more costly medical interventions.\textsuperscript{25,26,27}

Eliminating sex stereotyping and gender identity from the scope of discrimination on the basis of sex, the proposed rule would exacerbate discriminatory practices in the healthcare sector. Healthcare providers and issuers would no longer face consequences for refusing to treat or cover services as a result of a person’s gender identity or expression. This exemption would create significant barriers to care for LGBTQ+ individuals, especially those living in rural areas, with limited access to health services.

In line with its mission to “enhance and protect the health and well-being of all Americans,” HHS should uphold and strengthen policies and regulations that increase access and protect against discrimination for LGBTQ+ Americans. TFAH is concerned that the proposed rule would achieve the opposite effect.

**Effects on People Living with Disabilities**

One in four Americans has some type of disability.\textsuperscript{28} Although people living with disabilities are slightly more likely to have health insurance than those without disabilities, they still face

\textsuperscript{28} CDC. (2019). Disability Impacts All of Us. \url{https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html}. 4
numerous obstacles to accessing adequate health care. For example, they are more likely to report difficulties with finding a usual source of care, accessing care in a timely fashion, communicating effectively with providers, finding accessible medical facilities and equipment, and obtaining specialty services, such as home care.

Section 1557 includes a number of anti-discrimination protections for people living with disabilities. In its 2019 comment letter, HHS requests feedback on amending the following provisions, among others:

- Exempting covered entities with fewer than 15 employees from notifying people living with disabilities of the auxiliary aids and services that are available to them.
- Exempting existing buildings from complying with accessibility standards outlined elsewhere in Section 1557, unless those buildings undertake new construction or alterations.
- Exempting covered entities from providing reasonable accommodations for people living with disabilities if said entities can demonstrate that doing so would cause “undue hardship” to their business or organization.

These proposed measures would create additional loopholes allowing covered entities that provide services to people living with disabilities to work against the best interests of those they serve. Eliminating or relaxing Section 1557’s protections for people living with disabilities would restrict access to health care for this population, leading to poorer health outcomes and higher costs. In contrast, helping people with disabilities access healthcare improves outcomes and prevent more costly complications. For example, one study found that smokers who had difficulty walking were 20 percent less likely to be asked about their smoking history during an annual exam, even though smoking is severely debilitating in populations with limited

30 Ibid.
Another study showed that people with disabilities receive less preventive care, and as a result are more likely to die from preventable diseases such as breast cancer than non-disabled patients. By not giving this population the resources and care they deserve due to bias or incorrect assumptions, the proposal could expose people with disabilities to increased risk of morbidity and mortality, unnecessarily raising costs for patients and the system in the process. TFAH strongly opposes efforts to decrease access to supports for people living with disabilities.

**Effects on People with Limited English Proficiency (LEP)**

Navigating the health care system can be extremely difficult and stressful, even for native English speakers. For those with LEP, an interpreter can facilitate meaningful communication between the patient and the health care provider, enabling proper diagnoses, informed consent, culturally and linguistically appropriate treatment, and medication adherence.

The proposed rule would remove requirements for covered entities to provide key information, language assistance, and health aids without charge to individuals with LEP.

Under current regulations, individuals who wish to file a complaint with the Office for Civil Rights but who do not speak or understand English are assisted by taglines written in the top 15 non-English languages in their state. This is consistent with a long history of civil rights regulations requiring the posting of notice of rights, and these taglines are critical for patients and their families, as they provide a resource for them to understand their rights and navigate the system. Taglines are well-supported by existing federal and state regulations, guidance and practice and are a cost-effective approach to ensure that covered entities are not overly burdened. The proposed rule would also hinder access to assistance by removing the requirement to post these taglines. As a result, LEP individuals may reduce their contact with the health care system even in medically necessary situations. The Administration also wishes to deprioritize the importance of video-based interpreting services in favor of audio-only services. Video-based interpreting services can be crucial for patients with LEP who are hard of hearing or have mental health conditions. That should be a choice between the patient and the provider. Government

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42 Currently, taglines must be posted in significant publications and significant communications targeted to beneficiaries, enrollees, applicants, and members of the public, except for significant publications and significant communications that are small-sized, such as postcards and tri-fold brochures; in conspicuous physical locations where the entity interacts with the public; and in a conspicuous location on the covered entity's website accessible from the home page of the covered entity's website. 81 Fed. Reg. 31469, [https://www.federalregister.gov/d/2016-11458/p-1484](https://www.federalregister.gov/d/2016-11458/p-1484).
43 See Title VI Coordination Regulations, 29 C.F.R. § 42.405(d)(1); Marketplace and QHP issuer requirements, 45 C.F.R. § 155.205(c)(2)(iii); Medicaid Managed care plans, 42 C.F.R. § 438.10(d)(3); DOL WIOA Nondiscrimination requirements, 29 C.F.R. § 38.9(g)(3); USDA SNAP Bilingual Requirements, 7 C.F.R. § 272.4(b); and the 2003 HHS LEP Guidance.
policymaking should not interfere with how a patient and provider communicate. The Administration’s assertion that these services are unnecessary because most people are proficient in English fails to consider the burden that millions of people with LEP still face.45

**Effects on Use of Preventive Services**

As described above, the proposed changes would hinder access to clinical care for multiple populations, including access to cost-effective and cost-saving clinical preventive health services, such as immunizations and routine disease screenings. We are concerned that the proposed rule would not only limit access to important services but actually increase costs and the risk for disease.

Immunizations are critical to saving lives and preventing disease and disability.46 Yet, children and adults in rural or underserved areas would face a higher risk of under-immunization if they or their parents are refused care at a local clinic for any the reasons listed above. Not only do rural residents already struggle with a limited access of quality health care, but rural children also already have lower vaccine rates than the rest of the nation.47 Optional vaccines – such as seasonal influenza and vaccines provided to adults – could be underutilized as a result of unreliable access to health care. Regular access to quality care is especially critical for vaccines requiring multiple doses, such as diphtheria, tetanus, acellular and pertussis (DTaP), measles, mumps and rubella (MMR) and rotavirus. The proposed rule would also exacerbate racial and ethnic disparities in vaccination, especially among adults, if people with limited English proficiency receive differential access to care. The 2016 National Health Interview Survey found racial/ethnic disparities among African American, Asian American, and Hispanic adults for TDAP, HPV, and numerous other vaccines.48

We are concerned that the changes proposed in this rule would place more communities at risk of outbreaks of entirely preventable diseases. For example, experts estimate that between 93-95 percent of the population must be fully vaccinated with the MMR vaccine to maintain herd

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immunity against measles.\textsuperscript{49} Herd, or community, immunity, is when a high enough threshold of vaccinated people protects those who are unable to be vaccinated, generally because of age or underlying health condition. Therefore any barrier to immunization, such as enabling providers to deny care for any reason, denying language assistance, or limiting patients from knowing their health care rights and the services available to them, would make communities vulnerable to outbreaks. This would be an even graver public health concern during a pandemic, when vast majorities of the population would need to receive vaccines quickly.

In addition, reduced access to clinical care would place a barrier for people to receive routine disease screenings. A number of barriers already exist for many Americans to access timely screenings, including affordability, availability, and accessibility.\textsuperscript{50} Having a usual source of care is associated with increased preventive service use\textsuperscript{51, 52}, so this rule change could exacerbate disparities and barriers to preventive care. Racial, socioeconomic and geographic disparities exist for cancer screening\textsuperscript{53, 54} and other preventive procedures,\textsuperscript{55} and we are concerned the rule changes would place more Americans at risk for delayed diagnosis and treatment. Delayed diagnosis and treatment would also lead to higher healthcare costs. The World Health Organization states that delays in cancer screening, diagnosis and care result in lower likelihood of survival, greater morbidity of treatment and higher costs of care.\textsuperscript{56}

\textbf{Effects on Patient Health}

Discrimination can be understood as a stressor that is associated with negative impacts on patients’ mental and physical health.\textsuperscript{57} Despite existing protections against discriminatory

practices, research demonstrates that various communities continue to face discrimination when interacting with health care systems.\textsuperscript{58, 59} We are concerned that the proposed rule would allow for increased discrimination and create barriers for communities to access health care services, further exacerbating poor health outcomes among communities, particularly among LGBT+ persons\textsuperscript{60} and racial and ethnic minorities.\textsuperscript{61}

The harmful effects of discrimination range across mental and psychological health outcomes. For example, self-reported and perceived cases of discrimination in health care settings are associated with increased risk of mood, anxiety, and substance use disorders.\textsuperscript{62} LGBT+ youths who endure discrimination exhibit emotional distress, suicidal ideation, self-harm, and depressive symptoms.\textsuperscript{63} Similarly, women who encounter discrimination based on gender experience poor emotional health, such as more loneliness and depression\textsuperscript{64}. We are concerned that the proposed rule would contribute to stressors among individuals who already face high rates of discrimination, and their mental health may worsen as a result.

Under the proposed rule, weaker protections against discrimination may also affect physical health and health behaviors. Various studies have found that perceived and prolonged discrimination may lead to high blood pressure or more serious cardiovascular disease.\textsuperscript{65} Poor cardiovascular health can increase long-term health care costs and place financial burdens on individuals, families, and our health care system. Individuals who face discrimination are also more likely to engage in unhealthy behaviors, such as smoking and alcohol misuse.\textsuperscript{66} Tobacco and alcohol misuse may last a lifetime, but legal protections may help address concerning rates of discrimination that lead to such health


behaviors. We are concerned that the proposed rule will have the opposite effect and may lead to worse individual and population health by allowing discrimination in health care settings.

**Effects on Health Departments and Public Health Agencies**

Health departments and public health agencies play a crucial role in promoting population health and preventing disease. They are responsible for a range of activities, including disease surveillance, screening, vaccination, health education, policymaking, and controlling the spread of infectious disease.

Section 1557 applies to all state and local public health agencies that receive federal financial assistance from HHS. Under HHS’s proposed changes, federal law may permit public health agencies and professionals to deny services to LGBTQ+ individuals; fail to provide supports to people living with disabilities; and/or fail to provide important health information to people with LEP.

Meanwhile, because the public sector does play an important safety net role in many parts of the country, we are concerned that condoning discrimination in the private sector may lead more people to seek care from public clinics, without a corresponding increase in their budgets.

It is imperative that public health agencies prioritize delivering evidence-based care and interventions to all people. TFAH strongly opposes efforts that would exempt public health agencies from performing key agency functions for specific populations or individuals.

**Conclusion**

By facilitating and allowing discrimination in clinics and communities, HHS’s proposed rule would have deleterious effects on population health, particularly among already marginalized populations. We respectfully urge HHS to maintain Section 1557’s current authority and scope.

If you have any questions, please contact Dara Lieberman, TFAH’s Director of Government Relations, at dlieberman@tfah.org.

Sincerely,

John Auerbach, MBA
President and CEO
Trust for America’s Health

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