



October 3, 2022

Melanie Fontes Rainer
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: 1557 NPRM; HHS-OS-2022-0012; RIN 0945-AA17; Nondiscrimination in Health Programs and Activities

Dear Director Fontes Rainer:

Trust for America's Health (TFAH) is grateful for the opportunity to respond to the Notice of Proposed Rulemaking under Section 1557 of the Affordable Care Act concerning "Nondiscrimination in Health Programs and Activities." TFAH is a non-profit, non-partisan organization that promotes optimal health for every person and community and makes the prevention of illness and injury a national priority. We believe that health equity must be foundational to policymaking at all levels of society. Among our priorities, TFAH supports efforts to improve social determinants of health, including access to high-quality healthcare, education, built environments, and economic stability,¹ as a means to address health inequities, prevent the emergence of disease, and improve overall wellbeing.

The anti-discrimination protections in health and health care offered by Section 1557 are crucial for communities that have been marginalized and medically underserved. TFAH applauds HHS and OCR for reinstating, reaffirming, and strengthening many of the protections from the 2016 rulemaking process surrounding Section 1557. We offer the following comments on specific sections of the rule below.

Background

Section 1557 of the Affordable Care Act prohibits discrimination in health care on the basis of race, color, sex, national origin, age, and disability. "Covered entities" that must comply with the law include all those receiving federal financial assistance.

In 2019, HHS issued a regulation that significantly narrowed the scope of Section 1557 protections compared to the initial 2016 rulemaking. Changes included limiting the applicability

¹ Centers for Disease Control and Prevention. (2021). *Social determinants of health: Know what affects health*. Retrieved September 29, 2022, from <https://www.cdc.gov/socialdeterminants/about.html>

of Section 1557 to fewer entities by excluding health programs administered by HHS from those covered entities and excluding sexual orientation and gender identity from the protections offered in Section 1557.

During the 2019 rulemaking process, TFAH commented regarding our concerns about the effects a reinterpretation of Section 1557 would have on women, LGBTQ+ individuals, people with disabilities, people with limited English proficiency (LEP), and overall public health.² Nevertheless, HHS finalized the rule as proposed in 2020.

This 2022 rulemaking process proposes to return to the original agency interpretation of Section 1557. TFAH strongly supports the proposed regulation's intention to reapply and reaffirm the anti-discrimination protections in Section 1557.

Nondiscrimination in Health Programs and Activities - Application (§ 92.2)

TFAH strongly supports requiring health programs administered by HHS to abide by the non-discrimination protections of Section 1557. Covered entities under this proposed rule will apply non-discrimination requirements to:

1. every health program or activity, any part of which receives Federal financial assistance, directly or indirectly, from the Department;
2. every health program or activity administered by the Department;
3. every program or activity administered by a Title I entity.

This proposal is consistent with the 2016 rule and will return to a stronger scope of protections.

Applying non-discrimination across the entire healthcare and public health system is important to ensure that communities that have been marginalized and medically underserved will be treated with dignity and respect no matter where they go to receive prevention, public health, or care services.

Equal Program Access on the Basis of Sex (§ 92.206)

TFAH supports reinstating regulatory protections from discrimination on the basis of sex, including pregnancy, sexual orientation, gender identity, and sex characteristics, consistent with the statutory text of Section 1557 and Congressional intent.

In 2019, TFAH expressed concern regarding the impact the removal of these specific demographic protections from Section 1557 would have on women and the LGBTQ+ community. We cautioned that without protections from Section 1557, women could be denied care due to hospitals' and providers' religious beliefs. This is especially problematic in the context of pregnancy, where denial of care during pregnancy could result in injury or death. The U.S. already has the third highest maternal mortality rate among countries in the Organisation for Economic Co-operation and Development (OECD) with 23.8 maternal deaths per 100,000 live

² Auerbach, J. (2019). In Office for Civil Rights, U.S. Department of Health and Human Services (Ed.), *HHS-OCR-2019-0007; RIN 0945-AA1; comments in response to proposed rulemaking: Nondiscrimination in health and health education programs or activities* Trust for America's Health. Retrieved September 29, 2022, from https://www.tfah.org/wp-content/uploads/2020/06/CommentsOnACA_sec15578919.pdf

births in 2020.³ These rates have increased from 2018 (17.4 maternal deaths per 100,000 live births) and 2019 (20.1 maternal deaths per 100,000 live births) prior to the reinterpretation of Section 1557.⁴ While it is impossible to measure the impact of the 2019 rule, these trends are worrisome regardless and require optimal protection of the rights of pregnant people to seek care.

Further, different demographic groups do not bear the burden of maternal mortality equally. Non-Hispanic Black women experienced 55.3 deaths per 100,000 live births in 2020, nearly 3 times the rate for non-Hispanic white women over the same time period (19.1 deaths per 100,000 live births).⁵ Because of the intersectional nature of health inequities, Section 1557 cannot meaningfully protect communities that have been marginalized and medically underserved if entire characteristics like sex or pregnancy are denied anti-discrimination protections. Accordingly, TFAH supports the proposed rule's reaffirmation of Section 1557 protections on sex and pregnancy so that Americans will be more insulated from discrimination based on a more comprehensive set of identities.

During the previous rulemaking process, TFAH also expressed concern about the elimination of gender identity and sex characteristics from the anti-discriminatory protections in Section 1557. We noted that this step would intensify discrimination in healthcare:⁶

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.

Indeed, LGBTQ+ communities experience myriad health inequities. TFAH's report, *Pain in the Nation: Alcohol, Drug, and Suicide Epidemics*,⁷ notes that 47 percent of high school students who identify as lesbian, gay, or bisexual and 54 percent of high school students who reported having sex with same-sex partners reported seriously considering or attempting suicide, compared to 15 percent of heterosexual high school students and 19 percent of high school students who reported only opposite-sex sexual partners.⁸ Meanwhile, transgender people report

³ Organization for Economic Co-Operation and Development. (2022). *Health status: maternal and infant mortality*. Retrieved September 29, 2022, from <https://stats.oecd.org/index.aspx?queryid=30116#>

⁴ Organization for Economic Co-Operation and Development. (2022). *Health status: maternal and infant mortality*. Retrieved September 29, 2022, from <https://stats.oecd.org/index.aspx?queryid=30116#>

⁵ Hoyert, D. L. (2022). *Maternal mortality rates in the united states, 2020*. NCHS Health E-Stats. Retrieved September 29, 2022, from <https://www.cdc.gov/nchs/data/hestat/maternal-mortality/2020/maternal-mortality-rates-2020.htm#Table>

⁶ Auerbach, J. (2019). In Office for Civil Rights, U.S. Department of Health and Human Services (Ed.), *HHS-OCR-2019-0007; RIN 0945-AA1; comments in response to proposed rulemaking: Nondiscrimination in health and health education programs or activities* Trust for America's Health. Retrieved September 29, 2022, from https://www.tfah.org/wp-content/uploads/2020/06/CommentsOnACA_sec15578919.pdf

⁷ Warren, M. (2021). *Pain in the nation: Alcohol, drug, and suicide epidemics, special feature: COVID-19 and trauma* Trust for America's Health, Well Being Trust. Retrieved September 29, 2022, from https://www.tfah.org/wp-content/uploads/2021/05/2021_PainInTheNation_Fnl.pdf

⁸ Warren, M. (2021). *Pain in the nation: Alcohol, drug, and suicide epidemics, special feature: COVID-19 and trauma* Trust for America's Health, Well Being Trust. Retrieved September 29, 2022, from https://www.tfah.org/wp-content/uploads/2021/05/2021_PainInTheNation_Fnl.pdf

high rates of negative or discriminatory experiences with healthcare providers, including 25 percent who reported experiencing a provider who was unwilling to provide them with gender-affirming care and 18 percent who reported experiencing a provider who was unwilling to see them at all.⁹ As with sex and pregnancy, transgender people of color are more likely to have these negative experiences: they were 10 percentage points more likely than transgender white people to report experiencing a provider who was unwilling to provide them with gender-affirming care or unwilling to see them at all (38 percent and 28 percent, respectively).¹⁰

Reapplying anti-discrimination to sexual orientation and gender identity will strengthen healthcare access and reduces discrimination against women and LGBTQ+ Americans. TFAH strongly endorses the proposed rule's reestablishment of these protections.

Effective Communication for Individuals With Disabilities (§ 92.202), Accessibility for Buildings and Facilities (§ 92.203), Accessibility of Information and Communication Technology for Individuals With Disabilities (§ 92.204)

TFAH supports protections for people with disabilities proposed throughout this rule, including:

1. Reaffirming the requirement that covered entities must provide effective communication to people with disabilities in the form of provision of auxiliary aids and services to individuals with impaired sensory, manual, or speaking skills, for free, so that they may fully utilize services;
2. Forbidding covered entities from denying services to qualified individuals with disabilities because the covered entities' facilities are inaccessible to or unusable by individuals with disabilities; and
3. Ensuring that information and communication technologies are accessible to people with disabilities.

Because people with disabilities so often encounter a healthcare system that is not designed with their access in mind,¹¹ it is important to consider the special protections these populations deserve in order to ensure they have meaningful healthcare access. As the Centers for Disease Control and Prevention notes, improving healthcare access for people with disabilities can improve health outcomes and prevent costly health complications including those associated with smoking, obesity, mental illness, and lack of access to preventive care.¹²

TFAH is particularly pleased with the proposed rule's consideration of emergent communication technology for people with disabilities. The COVID-19 pandemic has greatly accelerated the

⁹ Medina, C., Santos, T., Mahowald, L., & Gruberg, S. (2021). *Protecting and advancing health care for transgender adult communities*. Center for American Progress. Retrieved September 29, 2022, from <https://www.americanprogress.org/article/protecting-advancing-health-care-transgender-adult-communities/>

¹⁰ Medina, C., Santos, T., Mahowald, L., & Gruberg, S. (2021). *Protecting and advancing health care for transgender adult communities*. Center for American Progress. Retrieved September 29, 2022, from <https://www.americanprogress.org/article/protecting-advancing-health-care-transgender-adult-communities/>

¹¹ Centers for Disease Control and Prevention. (2020). *Disability barriers to inclusion*. Retrieved September 29, 2022, from <https://www.cdc.gov/ncbddd/disabilityandhealth/disability-barriers.html>

¹² Centers for Disease Control and Prevention. (2020). *Disability and health related conditions*. Retrieved September 29, 2022, from <https://www.cdc.gov/ncbddd/disabilityandhealth/relatedconditions.html>

utilization of telehealth in the healthcare system.¹³ These provisions will help people with disabilities leverage such technologies to increase their access to healthcare rather than perpetuate existing access inequities for people with disabilities.

Meaningful Access for Limited English Proficient Individuals (§ 92.201)

TFAH supports the proposed rule’s protections for people with limited English proficiency including reestablishing requirements that covered entities take reasonable steps to provide meaningful access to each limited English proficient individual “eligible to be served or likely to be directly affected” by its health programs and activities.

TFAH was concerned with the elimination of these protections in 2019 because navigating the healthcare system can be difficult, even for native English speakers. We noted that providing linguistic support for individuals with limited English proficiency “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.”¹⁴ Reaffirming these supports for those with limited English proficiency will facilitate these communities’ access to healthcare services.

Data Collection

The proposed rule notes a history of support for requirements that covered entities collect additional data beyond those required by the referenced statutes and their regulations. This could include data on race, ethnicity, language, sex, gender, gender identity, sexual orientation, disability, and age, so that covered entities can better plan how to meet the needs of those populations. Currently, these data remain largely uncollected for many demographic subgroups which makes it difficult, if not impossible, to assess civil rights compliance for such groups.

Rather than codifying a specific set of data collection measures, the proposed rule is soliciting feedback on HHS and OCR using existing authorities to create dynamic and responsive civil rights data collection structures not unlike how the Department of Education collects civil rights data. TFAH supports such civil rights data collection measures and agrees with HHS and OCR that requesting civil rights compliance data under existing authorities will allow the Department to swiftly address emergent civil rights issues. Additional data collection comes with resource, time, and financial costs as well as a risk that individuals will be reluctant to provide these data out of concerns and/or fear of discrimination. However, the benefit of collecting these data outweigh their costs and risks as long as it is used effectively to ensure that Section 1557 is protecting civil rights in healthcare.

¹³ Anderson, J. T. L., Bouchacourt, L. M., Sussman, K. L., Bright, L. F., & Wilcox, G. B. (2022). Telehealth adoption during the COVID-19 pandemic: A social media textual and network analysis. *Digital Health*, 8, 20552076221090041.

¹⁴ Auerbach, J. (2019). In Office for Civil Rights, U.S. Department of Health and Human Services (Ed.), *HHS-OCR-2019-0007; RIN 0945-AA1; comments in response to proposed rulemaking: Nondiscrimination in health and health education programs or activities* Trust for America's Health. Retrieved September 29, 2022, from https://www.tfah.org/wp-content/uploads/2020/06/CommentsOnACA_sec15578919.pdf

Conclusion

By reaffirming and strengthening the original interpretation of Section 1557 of the ACA, HHS' proposed rule will protect millions of Americans from discrimination, helping facilitate their access to critical healthcare services. We applaud OCR and HHS for recognizing the importance of the anti-discriminatory protections of Section 1557 and ensuring that they will be applied with maximum efficacy in this rule.

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

Sincerely,

A handwritten signature in black ink, appearing to read "J. Nadine Gracia". The signature is fluid and cursive, with a long horizontal stroke at the end.

J. Nadine Gracia, MD, MSCE
President and CEO
Trust for America's Health