

October 3rd, 2022

Melanie Rainer
Director for Office for Civil Rights
U.S. Department of Health and Human Services
Office for Civil Rights (OCR)
Attention: 1557 NPRM (RIN 0945-AA17)

Submitted online via <https://www.regulations.gov>

RE: Nondiscrimination in Health Programs and Activities Proposed Rule Section 1557

Dear Director Melanie Rainer:

[United States of Care](#) (USofCare) is pleased to submit the following comments in response to the proposed rule to revise the implementing regulation for Section 1557 of the Affordable Care Act (ACA) for the purpose of advancing health equity and reducing disparities in health care. At USofCare, a foundational part of our work is centered on eliminating inequities in health care, and we applaud the Administration's commitment to that shared goal through this proposed rule.

USofCare is a nonpartisan nonprofit working to ensure everyone has access to quality, affordable health care regardless of health status, social need, or income. We drive change at the state and federal level, in partnership with everyday people, business leaders, health care innovators, fellow advocates, and policymakers. Together, we advocate for new solutions to tackle our shared health care challenges — solutions that people of every demographic tell us will bring them peace of mind and make a positive impact on their lives. After listening to people tell us about what they need from their health care, USofCare recently released a [set of twelve concrete and achievable](#) solutions to help us build a fairer system.

These twelve solutions are derived from four goals for the health care system that continuously rose to the top when talking to people around the country about what works and what is lacking in their health care. Two of these goals for the health care system are that people should have health care they can [depend on as life changes](#) and a health care system that is [understandable and easy to navigate](#).

Background

As you know, the landmark provision of the ACA, Sec. 1557, prohibits discrimination on the basis of race, color, national origin, sex, age, or disability in certain health programs or activities and is one of the government's most powerful tools to ensure nondiscriminatory access to health care. USofCare is pleased to submit our comments on these proposed rules based on our deep listening work conducted with people across the country.

Provisions of the rule change will lead us to a system that works towards achieving equitable health care for people. **USofCare applauds HHS for reassessing the 2020 rule interpretation of Sec. 1557 and acknowledging that the interpretation from the previous Administration was not sufficient in eliminating barriers and discrimination from health care.** The 2020 rule weakened and undercut considerable

pieces of the original 2016 rule, and we are pleased to see the current Administration make needed revisions. This is particularly important because, in the years since the 2020 rule took effect, we have seen health disparities exacerbated and brought to the forefront of our national conversation on health care. The COVID-19 pandemic showcased the health inequities existing in our communities through [higher rates of infection in communities of color due](#) to several factors, such as increased exposure due to work that cannot be done remotely, and longstanding racism in the health care system. Further exacerbating disparities, [22 state legislatures](#) around the country have introduced and/or passed bills to ban gender-affirming care for transgender youth in an unprecedented fashion.

It has become even more clear since 2020 that a more expansive interpretation of Sec. 1557-- that not only strives to prevent specific instances of discrimination but works within the system to lessen the impact of health inequities on communities-- is critical for reaching our goals for a health care system that works for everyone.

USofCare's comments focus on five sections of the proposed rule:

- 1) **Applicability.** USofCare strongly encourages HHS to broaden the applicability of protections to ensure that nondiscrimination requirements reach as many people as possible, and we provide select examples of where innovation in telehealth can support such an endeavor.
- 2) **Notices.** USofCare strongly supports the proposed reinstatement of requirements for covered entities to provide notice of nondiscrimination and language assistance services and auxiliary aids and services, and we highlight examples from our listening work that reiterates the importance of maintaining such policies.
- 3) **Data Sharing.** USofCare supports language in the proposed rule explicitly prohibiting covered entities from using algorithms to discriminate against people.
- 4) **Trainings.** US ofCare strongly supports new requirements to ensure relevant employees and providers of covered entities have the training necessary to comply with the policies and procedures outlined in Sec. 1557 and recognizes that the delivery of culturally appropriate and responsive care is of paramount importance.
- 5) **Religious Exemptions.** USofCare recognizes the sincerely held religious beliefs of many within our health care system, and also recognizes the need to ensure that those beliefs do not impede, prohibit, obstruct, or limit access to - delivery of - care for people who need these essential services.

The following sections highlight USofCare's position on each of these proposed changes. Where possible, we uplift voices of real people who engage with the health care system at the patient level, and whose input and perspectives have shaped US of Care's policy agenda and advocacy.

Applicability

USofCare strongly supports HHS applying these rules so that nondiscrimination standards are required across the broad range of HHS's administered health plans and activities. By reinstating these requirements broadly, more people will benefit from the protections this proposed rule would provide, moving the nation's health care system closer to achieving the aim of eliminating inequities. This policy change brings the Sec. 1557 requirements back in line with ACA statute and will help address disparities in access to quality, nondiscriminatory health care. Further, we appreciate HHS clarifying that this rule applies to health insurance issuers.

USofCare supports the inclusion of the specific provision regarding telehealth in Sec. 1557 rulemaking that would adopt the Health Resources and Services Administration (HRSA) definition of telehealth and include audio-only and text messaging among allowable communication technologies to promote health equity and access. As telehealth use has expanded under the COVID-19 pandemic, we have found that telehealth can be a strategy to help people – especially those who have been historically marginalized – access the care they need and reduce health disparities. However, without deliberate and careful efforts to address barriers, telehealth could worsen health disparities. Barriers to accessing telehealth [disproportionately impact](#) populations that have been historically marginalized, including people with disabilities and people with limited English proficiency (LEP). Individuals who can benefit from telehealth options should have access to it. Providers should ensure equal access for everyone – including people with disabilities and people with LEP – by providing them with the communication and other assistance they need to access care. **Furthermore, USofCare supports the adoption of HRSA’s definition of telehealth for the rule and recommends that the final rule list audio-only and text messaging specifically in the list of technologies HRSA includes in its definition, along with videoconferencing, the internet, store-and-forward imaging, streaming media, and terrestrial and wireless communications.**

Perspectives derived from USofCare’s listening work on telehealth include the following:

“Tablets, computers, [reliable] internet, and anything like that, most people don't have access to.”

- Rural focus group participant, Denmark, South Carolina

“Internet service can be a challenge; sometimes I have trouble maintaining a connection and we [the provider and the patient] have to keep calling each other back. You must have reliable internet access.”

- Rural focus group participant, Vance, South Carolina

Furthermore, USofCare strongly supports HHS reinstating nondiscrimination protections based on gender identity and sexual orientation. Research has shown that people who identify as LGBTQ+ face additional challenges and barriers in accessing regular preventive care as well as LGBTQ-specific treatment, such as gender-affirming care and HIV-prevention medication, or pre-exposure prophylaxis (PrEP). Up to 14 percent of LGBTQ+ people have reported having a [negative interaction](#) with a doctor or provider in a health care setting, and 15 percent have reported avoiding medical care altogether for fear of discrimination. That number rises to nearly 30 percent when considering just transgender people, who face additional health care challenges - one-third of transgender people have had to educate their provider on proper trans care.

Notices

USofCare supports the updated requirements that ensures entities explicitly notify individuals about the nondiscrimination protections established under Sec. 1557. By reinstating and/or reaffirming Sec. 1557’s nondiscrimination protections based on a range of categories, including, most notably, gender identity, but also sexual orientation, race, and ethnicity, of a person or an individual who that person associates with, people who identify as part of these historically marginalized communities will be less likely to avoid needed care for fear of discrimination from their provider. When we asked rural African American focus group participants what comes to mind when they hear the term health care, a number of the

responses included words like unfair, fear of being neglected, exclusion, assumptions, and lack of respect.

“Assumptions are made because of my size, my color, and now my age.” - Rural South Carolina focus group participant

USofCare supports HHS reinstating requirements for covered entities to provide notice of nondiscrimination and language assistance services and auxiliary aids and services. This includes support for HHS reinstating the requirement for covered entities to provide notice of the availability of language assistance services and auxiliary aids and the requirement for services to be provided in English and at least the 15 languages most commonly spoken and in alternate formats for individuals with disabilities who require auxiliary aids and services. This will help ensure people have clear communication, which will help them navigate the system.

Our work has led us to previously engage in conversations with community members who have highlighted a need for the navigation of the health system to be simplified:

“It's astonishing that you can't just go to a government website and type in how to find a low-cost dentist...There should be a [information] card with everything that you need to know on it that includes information like where to find assistance for things that affect people. Right now, no one knows where to go nor who to ask for help.”

- Caregiver, Chicago, Illinois

“Someone needs to explain things in plain terms so I know what they are saying.”

- Rural focus group participant, Denmark, South Carolina

USofCare recommends the following changes to the rule:

- Notices be required *in both* written and audio or video form to allow for more reach, as the proposed rule allows for notices to be provided through written translations or recorded audio *or* video clips.
- Notices include a prominently displayed phone number in English numerals as well as the language requested.
- Third-party translators utilized to translate notices should be proficient in communicating within the health care setting to ensure such notices are comprehensive yet easy to understand.

We also recommend that HHS consumer test and provide sample template notices in numerous languages for use by issuers and health providers . Doing so will ensure providers and issuers adhere to notice requirements while also ensuring translations are accurate and culturally appropriate.

Data Sharing

USofCare supports HHS’s proposal to make explicit that covered entities are prohibited from discriminating through the use of clinical algorithms on the basis of race, color, national origin, sex, age, or disability, as their use can exacerbate health inequities. The use of algorithms can encode existing racial biases that [disproportionately harm people of color](#) because they are built on biased data (like missing data) or flawed algorithms (like race-based adjustments), and there are important consequences:

algorithmic bias has led Black patients to receive [lesser quality care](#) and [reduced access to additional care](#). To combat this, health equity must be centered: algorithms should be intentionally designed with equitable frameworks and guardrails, there should be oversight over its use, and they should be regularly evaluated for biased or discriminatory outcomes to avoid discrimination on the basis of race, color, national origin, sex, age, or disability.

We have heard firsthand how people experience discrimination in health care:

“I've transported people before and I've been in a room with them. And with both persons of my color [White] and another. And the way that a physician has talked to them. Yeah, it's been different.” - Rural South Carolina focus group participant

“Ethnic background, it's [access to treatment] always ethnic background. It's always gonna be an issue.”

- Focus group participant, Texas

Trainings

USofCare strongly supports new requirements in the proposed rule that requires employees at entities subject to Sec. 1557 be trained in the policies and procedures of the relevant statute. For the first time, entities subject to Sec. 1557 will be required to train relevant employees in the proper provision of language assistance services for LEP individuals, reasonable accommodations and proper modifications for people with disabilities, and general requirements and nondiscrimination policies. [One in five people](#) have experienced discrimination in the health care system, and required training will increase the ability of entities to effectively meet the health needs of both people who are LEP, people with disabilities, and other people who have faced discrimination within the health care system. **While we applaud the inclusion of training requirements, we recommend the final rule be explicit about which staff are required to undergo training, rather than rely on covered entities to determine the relevant staff to take training.**

We have heard from people about the need for more training:

“There needs to be special training of the right doctors and nurses trained to deal with different types of population.”

- Focus group participant, Texas

HHS can look to Colorado’s innovative “Colorado Option” Standardized Health Benefit plan, which includes [important requirements](#) for customer-facing carrier staff to complete cultural competency or related trainings. This ensures those who work with patients are familiar with the unique needs of specific populations and the continuing effects of health inequities within the health care system. USofCare [incorporated](#) a number of recommendations to ensure health equity and cultural competency are centered as part of that state’s rollout of its Colorado Option, including increased adherence to training requirements and required language accessibility services, and we urge HHS to look to these recommendations when finalizing the Sec. 1557 rules.

The proposed rule also outlines compliance mechanisms to ensure entities are complying with the spirit of Sec. 1115’s nondiscrimination protections. While USofCare appreciates HHS’s decision to establish different mechanisms for enforcement based on the severity of a complaint, it is important to ensure that enforcement is level, targeted, and constant to ensure long-term adherence to the non-discrimination provisions in Sec. 1557.

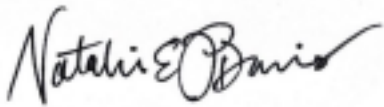
Religious Exemptions

US of Care strongly supports the ability of people to access health care regardless of a specific provider's refusal to provide care due to their sincerely held religious beliefs. We appreciate HHS's decision in the proposed rule not to include a blanket exemption for covered entities to opt out of the provision of certain forms of care. Instead, for the first time, the proposed rule establishes a process through which affected entities may raise concerns about providing care that may violate their religious beliefs. While these individuals may have the right to contest their requirement to provide such services, this process should not impede people from receiving needed care from a similar but different provider. Should an individual entity or provider's religious beliefs interfere with the provision of medical care, people deserve timely access to treatment from someone with whom there is no personal objection to the delivery of these services.

Conclusion

We appreciate the opportunity to provide comments in response to the proposed rule to revise implementing regulation for Sec. 1557 of the Affordable Care Act (ACA) for the purpose of advancing health equity and reducing disparities in health care. USofCare shares the Administration's commitment to eliminating health inequities and we applaud steps taken by HHS's Office for Civil Rights (OCR) to advance policies eliminating barriers and discrimination in health care. The proposals in this rule will strengthen nondiscrimination protections, and we encourage OCR to continue to promulgate policies that expand these protections further to ensure that everyone has quality, affordable health care free from discrimination.

Please consider our team at United States of Care a resource and do not hesitate to reach out to Lisa Hunter, Senior Director of Policy and External Affairs, at lhunter@usofcare.org, or Liz Hagan, Director of Policy Solutions, at ehagan@usofcare.org with questions regarding these comments.



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