August 7, 2019

The Honorable Alex Azar
Secretary
Department of Health and Human Services
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, D.C. 20201

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

Dear Secretary Azar:

Thank you for the opportunity to comment on the proposed rule “Nondiscrimination in Health and Health Education Programs or Activities.” The Robert Wood Johnson Foundation (RWJF) has a long history working to ensure that everyone in the United States has access to affordable, quality health care. Therefore, we have concerns about the implications of the proposed rule.

RWJF is the nation’s largest philanthropy dedicated to improving health and health care in the United States. Since 1972, we have worked with public and private-sector partners to advance the science of disease prevention and health promotion; train the next generation of health leaders; and support the development and implementation of policies and programs to foster better health across the country, including high-quality health care coverage for all. We are working with others to build a national Culture of Health that provides everyone in America a fair and just opportunity to live the healthiest life possible.

Our vision of a Culture of Health includes the principles that:

- Good health flourishes across geographic, demographic, and social sectors.
- Attaining the best health possible is valued by our entire society.
- Individuals and families have the means and the opportunity to make choices that lead to the healthiest lives possible.
- Business, government, individuals, and organizations work together to build healthy communities and lifestyles.
- No one is excluded.
- Everyone has access to affordable, quality health care because it is essential to maintain, or reclaim, health.
- Health care is efficient and equitable.
- The economy is less burdened by excessive and unwarranted health care spending.
- Keeping everyone as healthy as possible guides public and private decision-making.
Furthermore, our work is rooted in the understanding that health equity is crucial for achieving a Culture of Health. RWJF works from a definition of health equity that states: Health equity means that everyone has a fair and just opportunity to be as healthy as possible. This requires removing obstacles to health such as poverty, discrimination, and their consequences, including powerlessness and lack of access to good jobs with fair pay, quality education and housing, safe environments, and health care.

Given the Foundation’s long history working to expand access to care and to ensure that everyone has an opportunity to be as healthy as possible, RWJF asks the Department not to finalize the proposed rule. We are concerned that the rule will make certain groups of people more vulnerable to discrimination in health settings and less able to access needed services and assistance. The existing regulations governing Section 1557 of the Affordable Care Act (ACA) provide robust protection from discrimination. In order to achieve health equity, federally assisted and administered health programs and activities must address multiple forms of discrimination in multiple types of settings. Accordingly, we believe that the proposed rule moves in the wrong direction. If adopted in its current form, the rule significantly narrows nondiscrimination obligations while also moving federal policy away from the vigorous enforcement of those protections that do remain. In particular, we are concerned about the Department’s attempts at limiting the scope of enforcement and protections (including which entities are subject to Section 1557), changing requirements for language access, altering provision that provide strong support for people with disabilities, and modifying the current definition of discrimination based on sex. Furthermore, we believe that these provisions might allow for insurance benefit designs that are tantamount to pre-existing conditions exclusions, the elimination of which was one of the primary benefits for consumers of the ACA and a long-standing bipartisan policy goal.

Limiting Enforcement and Scope of Protections

The proposed rule generally attempts to narrow the scope of Section 1557 nondiscrimination protections in ways that are concerning and impede progress toward a more equitable health system. In particular, the proposed rule seeks to narrow the entities covered by the rule so that only specific health plans that receive federal funding would be covered as opposed to an insurer’s entire business. Furthermore, the Department of Health and Human Services (HHS) seeks to exempt other programs run by HHS. The regulation does not specify which programs, but given the scope of HHS’ work, this raises significant questions about numerous ways people could be affected by the proposed rule. In addition, the proposed rule removes the regulatory recognition of private enforcement rights on behalf of individuals who believe that they have been subjected to discrimination while simultaneously curtailing government enforcement efforts. The weakening of requirements to fully notify individuals about their rights under Section 1557, accompanied by rescinding requirements for taglines in non-English languages and removing language that specifies assistance for people with disabilities further erodes robust enforcement of nondiscrimination safeguards. Taken as a whole, these changes will mean that fewer people will either understand their rights or avail themselves of nondiscrimination protections.
For people who have experienced discrimination based on gender or gender identity, sexual orientation, race, color, national origin, age, or disability, the proposed changes remove important regulatory safeguards against the discrimination often faced by many in health settings.

The problems created by the proposed rules may be especially acute with respect to health care itself. The Foundation has found that trust and respect are key features to successful health care treatment. Patients, particularly those with lower incomes, often do not feel respected by health care providers. Where that sense of respect is missing and the perception is one of disrespect, such a result correlates with lower compliance with recommended treatments. Furthermore, numerous studies have documented discrimination based on race and ethnicity, gender, gender identity, sexual orientation, disability, and combinations of these categories. HHS should be doing all that is possible to ensure that people are treated fairly and with dignity, and this rule could undermine progress in building trust and respect rather than making needed advancements.

**Discrimination Based on Limited English Proficiency**

Current Section 1557 regulations require covered entities to take reasonable steps to ensure that people with limited English proficiency are able to receive the care they need. The current regulations also require that taglines on important documents are written in multiple languages so that people with limited English proficiency know how to access help in a language they understand. These provisions, along with the other existing language access provisions, are an important protection for the 25 million people in the country who report that they do not speak English very well.

Numerous studies have demonstrated that language can be a barrier to quality health care. The current regulations are an important step toward ensuring that all people in the United States are able to get the care they need. RWJF’s own work on language access through a significant program, Hablamos Juntos (Together We Speak), demonstrated that providing interpreters for patients who were more comfortable speaking in Spanish than English led to increased satisfaction and higher quality of care.

In order to ensure that everyone in the United States is able to access the care they need regardless of national origin or level of English fluency, we recommend maintaining the current standards for providing language access as opposed to adopting the proposed regulations, which offer fewer guarantees of adequate language access.

**Discrimination Based on Disability**

The proposed rule also changes other provisions providing critical protections to individuals with disabilities as well. For example, in addition to limiting access to care based on limited English proficiency, the proposed regulation could also limit access for people who require auxiliary aids and services to effectively communicate due to a disability. The proposed rule removes clarifying language
from the rule adopted in 2016 that states that covered entities must provide “equipment and devices” that are necessary for effective communication. This change in the proposed rule, when combined with the weakening of requirements to notify people of their rights under 1557, means that people with disabilities may not even know that they have the right to resources to ensure they can participate fully in their care.

Recently RWJF has made a commitment to champion disability inclusion in philanthropy and within our own work. As we incorporate equity in our work, we had to recognize that disability-related issues are not a niche grantmaking area but intersect with almost everything we do. Given that people with disabilities are less likely to have a college degree, more likely to be unemployed, and already face significant barriers to accessing health care, we think it is important to ensure that existing obstacles are removed for people with disabilities.

**Discrimination Based on Gender Identity and Sexual Orientation**

Discrimination and lack of access to providers attuned to the needs of sexual and gender minorities present a serious barrier to health care for lesbian, gay, bisexual, and transgender (LGBT) populations. The Foundation supports the existing regulatory definition of what constitutes discrimination on the basis of sex, which now includes gender identity and gender expression. RWJF recognizes that this is a question being examined by various courts, but believes that there is no need to change the definition in the regulations governing Section 1557 at this time, nor is there a need to remove protections for LGBT populations from the conforming amendments the Department has identified.

In various ways, the proposed rule would limit protections for LGBT people. By narrowing the definition of discrimination based on sex to exclude gender identity and sex stereotyping, the agency is limiting protections from discrimination for LGBT people. Such a change would also permit insurers, even in the case of plans that unequivocally and directly rely on federal financial assistance, to deny coverage for gender-affirming treatments. Furthermore, in the conforming amendments connected to the proposed rule, the Department proposes eliminating sexual orientation and gender stereotyping from additional HHS regulations. Overall, the proposed rule would make it easier for health providers and insurers to discriminate against LGBT people and to deny gender-affirming care to transgender patients.

RWJF is concerned about the implications of this rule given the level of discrimination that LGBT people face in the health care system. A recent survey conducted by RWJF, NPR, and the Harvard T.H.Chan School of Public Health found that 18 percent of LGBT people avoided medical care due to concerns about discrimination. Other research has shown that 29 percent of transgender people had experienced discrimination in health care settings. A literature review that examined health care disparities among LGBT youth found significant health challenges for this population, including difficulty discussing sexual orientation and gender identity with providers. An Institute of Medicine study further identified stigma as a barrier to accessing health care for LGBT populations.
Benefit Design

One of the most significant benefits of the ACA is that it eliminated the problem of people not being able to obtain health insurance because of a pre-existing condition. Proposing to narrow HHS’ interpretation of the scope of section 1557 would allow insurance plans not subject to the essential health benefit standard (i.e., large employer plans), as well as unsubsidized individual plans to employ discriminatory benefit designs. The most easily observable example of this type of conduct would be plans that put all of the drugs for a specific condition, such as HIV/AIDS, into a drug tier with high cost sharing as a means of discouraging enrollment. This conduct already has been observed by researchers who documented the use of drug tiering strategies that made certain health insurance plans unaffordable to people with serious conditions or disabilities. The current regulation on 1557 ensures that across all forms of coverage, insurers are barred from employing coverage rules that would discriminate against people with chronic conditions or disabilities. This protection should be retained.

RWJF is concerned that these proposed changes, along with other changes that significantly restrict which entities are covered by the rule (such as leaving out employer-based coverage and other nonsubsidized coverage), would reintroduce discriminatory benefit design, including drug tiering, and thus undo one of the most important benefits of the ACA. For these reasons, we ask the Department to not finalize the proposed rule and allow the existing regulations to stand.

We thank you for the opportunity to comment on the proposed rule. We look forward to continuing to work with the Department and other partners to ensure that everyone has the opportunity to achieve optimal health and well-being.

Sincerely,

Richard E. Besser, MD
President and CEO
Robert Wood Johnson Foundation