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October 3, 2022

VIA ELECTRONIC SUBMISSION

Melanie Fontes Rainer
Director
Office for Civil Rights
Department of Health and Human Services
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue, SW
Washington, D.C. 20201

RE: Nondiscrimination in Health Programs and Activities (Section 1557 NPRM), RIN 0945-AA17

Dear Director Fontes Rainer:

On behalf of The Leadership Conference on Civil and Human Rights, a coalition charged by its diverse membership of more than 230 national organizations to promote and protect the civil and human rights of all persons in the United States, and the undersigned organizations, we write in response to the notice of proposed rulemaking on Section 1557 of the Patient Protection and Affordable Care Act (ACA) that promotes nondiscrimination in health care. We write to express support for the proposed rule entitled "Nondiscrimination in Health Programs and Activities," published in the Federal Register on August 4, 2022.

Health care is a human right. Every person in our nation should be free to safely access health care without fear of discrimination, harassment, or persecution. Unfortunately, discriminatory health care systems and policies play an outsized role in the ability of people to access quality health care in the United States. Our members have advocated for Section 1557's full and complete implementation since it took effect on March 23, 2010.

Given the pervasive legacy of racism and other forms of discrimination in health systems and health policy, Section 1557 has represented a significant step toward rectifying centuries of policies and practices that have created worse health outcomes for communities of color, people with disabilities, women of color, LGBTQ people, Limited English Proficient (LEP) individuals, older adults and children, and other systemically marginalized groups.[1] Section 1557 addresses not only protections for each protected class covered, but the intersection of

[1] For the purposes of these comments, the term "systemically marginalized" references the institutional and system-based process where persons are intentionally removed, denied, and isolated from economic, sociopolitical, and cultural participation based on race, sex, immigrant status, income, disability status, pregnancy status, multi-generational living arrangements, LGBTQI+ identity, LEP status, and age.

those protections, properly recognizing that an attack on the civil rights of one group is an attack on the civil rights of all.

Although a number of federal laws prohibit several forms of discrimination, Section 1557 extends these protections to any health program or activity that receives federal funding, any health program or activity that the Department of Health and Human Services (HHS) administers, the health insurance marketplace, and all plans offered by insurers that participate in those marketplaces. This proposed rule not only clarifies the broad civil rights protections extended in Section 1557, but provides concrete tools to combat various forms of discrimination in health care.

Ultimately, this proposed rule is a landmark regulatory effort to address discrimination in health care. The Leadership Conference and the undersigned organizations strongly recommend that the proposed rule be finalized and implemented, and that the issues and recommendations raised below, as well as through separate comments from our coalition members, be strongly considered by the department.

I. The Proposed Rule Addresses Discriminatory Conduct that Disproportionately Impacts Communities at the Intersection of Multiple Protected Identities

Federal law has prohibited race discrimination in health care since the passage of Title VI of the Civil Rights Act of 1964. However, Title VI does not apply to all health care-related activities and programs, nor does it apply to all forms of discrimination in health care. Section 1557 therefore fills in a critical gap by extending antidiscrimination protections to patients at the intersection of multiple identities. We appreciate that the department has outlined the types of discrimination prohibited in Section 92.101 of the proposed rule. We strongly support the intersectional nature of Section 1557 and urge the department to identify other ways to address intersectional discrimination in the regulatory provisions of the 2022 proposed rule itself, such as including a specific recognition of intersectional discrimination in Section 92.101, as well as in other sections throughout the proposed rule.

The proposed rule proscribes many forms of discrimination that amplify the impacts of racism and other forms of bias in health care. For example, the proposed rule seeks to eliminate discrimination against Limited English Proficient (LEP) individuals and people living with disabilities — groups that are largely comprised of people of color. Likewise, Section 1557 proscribes sex discrimination in health care, and we recommend that the department explicitly expand upon what constitutes discrimination on the basis of sex in the final rule. As discussed further below, the proposed rule restricts discriminatory conduct against these groups, which will improve health care access and outcomes for people with multiple systemically marginalized identities.

A. The proposed rule requires adequate language access services that will improve health care access and outcomes

Improving language access services is a critical tool to addressing intersectional discrimination. LEP patients often experience inadequate or inaccurate interpretation by the provider, patient's family, or untrained staff, leading to greater patient risk and disparities in health outcomes. It has been long

recognized that the denial of adequate language services to LEP individuals constitutes discrimination on the basis of national origin, and there are clear intersections between LEP status and other forms of discrimination. According to the most recent data, 63 percent of LEP individuals are Latino and 21 percent are Asian/Pacific Islander.[2] Another study noted that a "substantial number of Asian Americans reported encountering racial discrimination and possessing limited English proficiency."[3] Robust language access resources and protections from discrimination are also key to ensuring that older adults, including the more than 6.5 million seniors over age 60 and 4 million people with Medicare who are LEP, can access care and services, receive important health care information in a language they understand, and are informed of their rights and how to enforce them.

The proposed rule improves language access by emphasizing that the definition of "limited English proficient individual" includes those who may be competent in English for certain types of communication (e.g., speaking or understanding), but still be LEP for other purposes (e.g., reading or writing).[4] This will ensure providers and other covered entities understand that people who have some English competency may still need translated written materials, for example. The proposed rule also ensures "meaningful access" to health care services by providing clarity on the steps providers and other covered entities must take to effectuate this goal. For example, the proposed rule requires covered entities to provide a qualified interpreter and translator when providing language services and requires human translators to review materials generated by machine translation in most cases.[5] Clarifying the definition of LEP and ensuring quality translation services will significantly reduce barriers to quality health care for these patients.

B. The proposed rule addresses health disparities by improving access for people with disabilities

Improving health care access for people with disabilities is critical to reducing health disparities, which are often compounded by pervasive ableism and intersecting systems of discrimination. For example, Black people are more likely to have a disability relative to White people in every age group, and according to the Centers for Disease Control and Prevention, three in 10 American Indian/Alaska Native people and one in four Black people live with disabilities.[6] Additionally, older adults with disabilities often experience discrimination based on both ageism and ableism.

The Americans with Disabilities Act and the Rehabilitation Act both prohibit discrimination against people with disabilities, though Section 1557 strengthens these antidiscrimination protections. The

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[2] Batalova, Jeanne, et al. "The Limited English Proficient Population in the United States in 2013." *Migrationpolicy.org*, 8 July 2015, https://www.migrationpolicy.org/article/limited-english-proficient-population-united-states-2013.
[3] Gee, Gilbert C., et al.. "Associations Between Racial Discrimination, Limited English Proficiency, and Health-Related Quality of Life Among 6 Asian Ethnic Groups in California." *American Journal of Public Health*, vol. 100, no. 5, May 2010, pp. 891-892., https://ajph.alphapublications.org/doi/pdf/10.2105/AJPH.2009.178012
[4] Ibid. at 58; Proposed Sec. 92.4.
[5] Proposed Sec. 92.210.
[6] "Adults with Disabilities: Ethnicity and Race." *Centers for Disease Control and Prevention*, 16 Sept. 2020, https://www.cdc.gov/ncbddd/disabilityandhealth/materials/infographic-disabilities-ethnicity-race.html.

proposed rule requires covered entities to proactively ensure patients with disabilities are provided with reasonable accommodations. For example, the department clarifies that a covered entity must provide modifications in the absence of a request when it had knowledge of an individual's disability or when the individual's disability is obvious.[7] In addition to a number of technical requirements that improve access, Sections 92.203 and 92.205 of the proposed rule preserve prior existing requirements for structural accessibility and the provision of reasonable modifications. We support these sections, and additionally recommend incorporating existing standards relating to accessible medical and diagnostic equipment that were developed by the United States.[8] These provisions, including these additional recommendations, are critical, especially considering that people with disabilities routinely report feeling unable to convey their medical needs to physicians or having those needs dismissed.

We also support the inclusion of Section 92.207(b)(6), i.e. the "integration mandate" that requires "services, programs, and activities [be administered] in the most integrated setting appropriate to the needs of qualified individuals with disabilities." It is necessary for the rule to specifically address the integration mandate given its role in ensuring disabled people are not segregated in health care settings. Far too often hospital systems and providers have pushed people with disabilities into long-term institutionalization due to their dependency on certain services, going against the rights given to disabled people in the Americans with Disabilities Act and the *Olmstead* decision,[9] and thus necessitating HHS to explicitly add the integration mandate in Section 1557.

C. The proposed rule recognizes various forms of sex discrimination that disproportionately impact health care access and outcomes

1. LGBTQ people

We are pleased that the department has articulated a clear and expansive explanation of discrimination on the basis of sex. We support the explicit inclusion of discrimination based on sex characteristics, including intersex traits, as such discrimination is inherently sex-based. We suggest that the language in Section 92.101(a)(2) be amended to explicitly include transgender status. While the terms "gender identity" and "transgender status" are often used interchangeably, there have been instances in which discrimination against transgender people has been attempted to be justified by raising distinctions between the two concepts, and we therefore recommend enumerating both in the regulatory text for clarity.

We strongly support the inclusion of proposed Section 92.206, which requires equal program access on the basis of sex and addresses the conditions that lead to health disparities among transgender people more broadly.[10] This section importantly clarifies that while providers may exercise clinical judgment when determining if a particular service is appropriate for an individual patient, they may not refuse

[7] Fed. Reg. at 47850.
[8] *See* Medical Diagnostic Equipment Accessibility Standards, U.S. Access Board, https://www.access-board.gov/mde/.
[9] *Olmstead v. Lois Curtis*, 527 U.S. 581 (1999).
[10] Fed. Reg. at 47865-68; Proposed Sec. 92.206.

gender-affirming care based on a personal belief that such care is never clinically appropriate. We suggest strengthening the language pertaining to providers complying with a state or local law as a justification for denying gender-affirming care to state unequivocally that Section 1557, as federal law, preempts any such state or local law restricting access to this care.

Additionally, we support proposed Section 92.207's prohibition of discrimination in the coverage of gender-affirming and transition-related care. Transgender and gender diverse people face significant barriers to health care access, such as coverage exclusions, waiting periods, high cost sharing, lack of access to providers, and determinations that gender-affirming care is cosmetic or not medically necessary. These barriers to care are further heightened for Black, Indigenous, and other transgender people of color, as well as transgender people with disabilities. The proposed rule aims to protect transgender, nonbinary, intersex, and gender diverse people from discriminatory benefit design and other practices by insurers that are contrary to well-established standards of care, and realigns regulatory protections with the medical standards of care put forth by major medical associations.

We support the restoration of explicit protections against discrimination on the basis of association in Section 92.209. This is consistent with longstanding interpretations of other antidiscrimination laws, which cover discrimination based on an individual's own characteristics or those of someone with whom they are associated or with whom they have a relationship. The proposed rule notes in the preamble that certain protected populations, including LGBTQ people, are particularly susceptible to discrimination based on association. An individual in a same-sex relationship or marriage could be subjected to discrimination based on their own and their spouse or partner's sex, whereas that same individual might not be similarly mistreated were they not in a same-sex relationship. The final rule must make clear that this kind of associational discrimination is within the scope of the rule's protections.

2. Pregnant people

Abortion is a critical part of the spectrum of reproductive health care. Since the Supreme Court permitted states to criminalize abortion in *Dobbs v. Jackson Women's Health Organization*, there have been reports of people experiencing pregnancy complications necessitating abortion, but being unable to access care.[11] Following the *Dobbs* decision, individuals — especially people of color, people with low incomes, immigrants, young people, people with disabilities, and LGBTQ people — are facing numerous logistical and legal barriers to accessing care with an increased threat of arrest and prosecution as states seek to criminalize abortion care. The consequences of the *Dobbs* decision will fall especially heavy on those who experience intersectional discrimination.

We support the department's inclusion of "pregnancy or related conditions" in the definition of sex discrimination in the proposed rule. However, especially in the wake of *Dobbs*, it is critical that the final rule explicitly name discrimination on the basis of termination of pregnancy as part of sex discrimination. "Termination of pregnancy" must be enumerated under prohibited sex discrimination in Section

[11] Feibel, Carrie. "Because of Texas Abortion Law, Her Wanted Pregnancy Became a Medical Nightmare." NPR, 26 July 2022, https://www.npr.org/sections/health-shots/2022/07/26/1111280165/because-of-texas-abortion-law-her-wanted-pregnancy-became-a-medical-nightmare

92.101(a)(2), and abortion care must be clearly and consistently included with "pregnancy or related conditions" throughout the final rule. Adding "pregnancy or related conditions, including termination of pregnancy" to the definition of sex discrimination and throughout the proposed rule will help to ensure that pregnant people are able to access life-saving care.

Additionally, we recommend that the prohibition on discrimination of pregnancy or related conditions, including termination of pregnancy, should not be listed under Section 92.208. Including "pregnancy or related conditions, including termination of pregnancy" discrimination could result in policies that are biased against single people who experience discrimination based on obtaining or having obtained an abortion. While this provision is welcome for ensuring robust enforcement against sex being used to determine eligibility for a health program in specific instances, including discrimination on the basis of abortion in this context could cause confusion that discrimination because of having had an abortion only occurs in a marital, parental, or family context. Entities writing policies will have clearer guidance if the department includes discrimination based on obtaining an abortion outside of Section 92.208.

II. The Proposed Rule Addresses Various Forms of Systemic Discrimination in Health Care and Methods of Prevention

The department properly notes that health disparities in the United States are directly attributable to persistent bias in the health care system. Both explicit and implicit discrimination serve as barriers to care, lead to lower quality care, and drive worse health outcomes for communities. Discrimination in health care is often systemic — deeply embedded within the policies, procedures, and practices of covered entities. The proposed rule addresses several major drivers of systemic discrimination, including antidiscrimination policies and procedures and algorithmic discrimination. The proposed rule takes a critical step toward addressing the ways in which discrimination manifests systemically in health care.

A. Section 1557 policies and procedures are a necessary step toward preventing discriminatory conduct in health care

The proposed rule notes that for patients with systemically marginalized identities, trust in their health care providers would increase if these patients were aware of their rights and how they can address their concerns directly to their health care providers, which would in turn improve these patients' overall health care experiences. However, existing Section 1557 policies and procedures requirements are disjointed, confusing, and ineffective. We support changes to the proposed rule that would streamline these requirements by requiring covered entities to adopt and implement written nondiscrimination policies against all forms of discrimination, including language and disability access procedures (collectively, Section 1557 policies and procedures).[12] The revised Section 1557 policies and procedures aim to prevent discrimination from occurring in the first place by ensuring covered entities have greater knowledge of their obligations under Section 1557. We support the notice of nondiscrimination requirements in Section 92.10, to help ensure that individuals receive information about their rights; know how to access interpreters, auxiliary aids, and services; and know how to file a complaint or a grievance. Greater notice

[12] Fed. Reg. at 47847; Proposed Sec. 92.8. The proposed rule also requires covered entities with 15 or more employees to adopt grievance procedures.

and transparency of information available to patients and greater understanding of what is required of providers will help to improve overall patient experiences and health care outcomes.

B. The proposed rule would prohibit the discriminatory use of clinical algorithms and crisis standards of care

The discriminatory use of clinical algorithms has no place in health care. Proposed Section 92.210 would 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 under Section 1557.[13] Many clinical algorithms dictate that Black patients, for example, must be more ill than White patients before they can receive treatment for a range of life-threatening conditions, including for kidney disease, heart failure, and pregnancy-related complications.

Similarly, crisis standards of care, which are also driven by clinical algorithms, have often reflected a bias against people with disabilities, people of color, and older adults. They typically prioritize care toward patients who are younger and do not have disabilities, excluding or de-prioritizing those who have certain health conditions, those who are presumed unlikely to survive in the intermediate or long term, and those believed to require greater resources to survive an acute episode of illness. This provision in the proposed rule is critical in addressing one of the most prevalent forms of systemic discrimination in health care today.

III. The Final Rule Must Ensure Robust Enforcement of Section 1557

Considering the enormity of discriminatory conduct in health care, Section 1557 requires rigorous enforcement in order to ensure marginalized groups can access quality health care. We are therefore pleased the proposed rule provides for robust enforcement of these critical civil rights provisions, consistent with existing law and the clear, unambiguous intent of Section 1557. Clarifications can be made to the final rule to ensure that even stronger enforcement mechanisms and remedies are available to patients.

A. The proposed rule must be clarified to ensure the availability of strong enforcement mechanisms and remedies

We support strong enforcement of Section 1557 and welcome the department's recognition that the law protects people who experience intersectional discrimination. To that end, we suggest that the department include explicit references to intersectional discrimination throughout implementing regulations, including Section 92.301. Section 92.301 must ensure that HHS will have clear and accessible procedures for individuals to file, and the agency to investigate and remediate, discrimination complaints, including intersectional discrimination complaints. The department must make explicit throughout implementing regulations that Section 1557 creates a health-specific, anti-discrimination cause of action that is subject to a singular standard, regardless of a plaintiff's protected class or classes.

[13] Ibid. at 176-187.

The former 2020 NPRM offered inaccurate and restrictive interpretations of the law and the types of activities and entities covered. The department therefore had limited enforcement power in preventing discrimination. We now offer strong support for the department's clarification that Section 1557 both provides an "independent basis for regulation of discrimination in covered health programs and activities" and is applicable to an expansive range of "health programs and activities," including those administered by the department itself, as well as health insurance plans.[14]

We also commend the department's clarification that Section 1557 applies to Medicare Part B.[15] For decades, the department erred in determining that Medicare Part B payments were not "federal financial assistance." As noted in one article, "[a]s a result, a hospital could pass Title VI certification and, through the racially exclusionary admission practices of its medical staff, remain segregated."[16] Moreover, many patients have been unable to sue their health care providers for discrimination on the basis of race, color, or national origin under Title VI. The proposed rule addresses this problem by applying a reasonable interpretation of "federal financial assistance" and clarifying that Medicare Part B providers are covered entities under Section 1557.[17] These clarifications are an important step in addressing discrimination in all health care settings.

B. The final rule must require disaggregated data collection

The availability of disaggregated demographic data supports the department's enforcement efforts. We commend the department for recognizing the critically important role demographic data plays in addressing discrimination and health disparities.[18] However, we are concerned the department does not, at minimum, require covered entities to collect disaggregated demographic data.

Better national standards and uniform data collection practices could have an outsized impact on efforts to narrow health disparities. HHS must require demographic data collection based on multiple demographic variables, including sex, race, ethnicity, primary language, age, gender identity, sexual orientation, and disability status. At the community and population levels, these variables, both individually and in combination, can reveal health disparities. For example, racial and ethnic minority women receive poorer quality care than racial and ethnic minority men, who receive poorer care than White men.[19] Spanish-

[14] Proposed Sec. 92.1.
[15] Fed Reg. at 47887-90.
[16] Smith, David B. "The Golden Rules for Eliminating Disparities: Title VI, Medicare, and the Implementation of the Affordable Care Act." *Health Matrix: The Journal of Law-Medicine*, vol. 25, no. 1, 2015, pp. 33-59., https://scholarlycommons.law.case.edu/healthmatrix/vol25/iss1/4
[17] The Proposed Rule clarifies this by defining "federal financial assistance" as "any grant, loan, credit, subsidy, contract (other than a procurement contract but including a contract of insurance), or any other arrangement by which the Federal Government, directly or indirectly, provides assistance or otherwise makes assistance available in the form of funds, services of Federal personnel, or real or personal property for less than fair market value."
[18] Fed. Reg. at 47856-7.
[19] Rosaly Correa-de-Araujo et al., *Gender differences across racial and ethnic groups in the quality of care for acute myocardial infarction and heart failure associated co-morbidities*, Women's Health Issues 44 (2006); Ann F. Chou et al., *Gender and racial disparities in the management of diabetes mellitus among Medicare patients*, Women's Health Issues 150 (2007).

speaking Hispanics experience poorer quality care than English-speaking Hispanics, who experience poorer care than non-Hispanic Whites.[20] Compared to women without disabilities, women with disabilities are more likely not to have regular mammograms or Pap tests.[21] Racial and ethnic minorities with disabilities experience greater disparities in diagnoses and utilization of assistive technology.[22]

While investigations of alleged discrimination sometimes focus on variations based on a single demographic variable, in our increasingly multicultural society, it is imperative that HHS's civil rights enforcement should support these types of analyses. This requires standardized categories and definitions for all these demographic variables and relevant combinations. The department must act decisively and require covered entities to collect demographic data, as existing data collection efforts are insufficient.

Additionally, the department must ensure that data collected is maintained safely and securely by the appropriate entities. Strict standards must be adopted to make clear that data cannot be used for negative actions such as immigration or law enforcement, redlining, or targeting of specific groups. While requests for data should be required, individuals' responses must be voluntary and should be self-reported to ensure accuracy. It is critical to train relevant staff on the collection of demographic data, including how to explain why data is being collected. These policies will help to ensure that data collected can be best utilized to prevent discrimination and disparities in health care access and outcomes.

CONCLUSION

The Leadership Conference on Civil and Human Rights and the undersigned organizations strongly encourage the administration to finalize this rule, with serious consideration given to the issues raised both within these comments and through separate comments from our coalition members. The proposed rule is a significant step towards addressing discrimination, and particularly for those experiencing discrimination due to the intersection of multiple identities. We appreciate the department's efforts to ensure robust implementation and enforcement of Section 1557 of the ACA throughout the health care system.

Thank you for the opportunity to submit our comments on the proposed rule. If you have any questions, please contact Peggy Ramin, policy counsel at The Leadership Conference, at ramin@civilrights.org.

Sincerely,

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[20] Eric M. Cheng, Alex Chen & William Cunningham, *Primary language and receipt of recommended health care among Hispanics in the United States*, J. General Internal Medicine 283 (2007); C. Annette DuBard & Ziya Gizlice, *Language spoken and differences in health status, access to care and receipt of preventive services among U.S. Hispanics*, Am. J. Public Health 2021 (2008).

[21] Marguerite E. Diab & Mark V. Johnston, *Relationships between level of disability and receipt of preventive health services*, Archives of Physical Medicine and Rehabilitation, 749 (2004).

[22] D.S. Mandell et al., *Racial/ethnic disparities in the identification of children with autism spectrum disorders*, Am. J. Public Health 493 (2009); H.S. Kaye, P. Yeager & M. Reed, Disparities in usage of assistive technology among people with disabilities, 20 Assist. Technol. 194 (2008).

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