LAWYERS' COMMITTEE FOR CIVIL RIGHTS UNDER LAW

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October 3, 2022

Via electronic submission[1]

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

RE: Comments on Regulatory Information Number (RIN) 0945-AA17, Nondiscrimination in Health Programs and Activities

Dear Director Fontes Rainer:

The Lawyers' Committee for Civil Rights Under Law ("Lawyers' Committee") submits these comments in response to the Department of Health and Human Services' ("HHS," "the Department") Notice of Proposed Rulemaking ("Proposed Rule," "NPRM") to express our support for the Proposed Rule entitled "Nondiscrimination in Health Programs or Activities," published in the Federal Register on August 4, 2022.

The Lawyers' Committee is a nonpartisan, nonprofit organization, formed in 1963 at the request of President John F. Kennedy to enlist the private bar's leadership and resources in combating racial discrimination and the resulting inequality of opportunity—work that continues to be vital today. The Lawyers' Committee uses legal advocacy to achieve racial justice, fighting inside and outside the courts to ensure that Black people and other people of color have voice, opportunity, and power to make the promises of our democracy real. For nearly 60 years, the Lawyers' Committee has been at the forefront of many of the most significant cases involving race and national origin discrimination. The Lawyers' Committee has a strong interest in eliminating systemic discrimination and structural barriers to health care experienced by people of color, including women and LGBTQ individuals, and to that end has served as *amicus curiae* in significant cases impacting access to healthcare. *See, e.g.*, *Pennsylvania v. Trump et al.*, 351 F. Supp. 3d 791 (E.D. Pa. 2019), *appeal filed*, No. 19-1189 (3d Cir. Jan. 23, 2019); *Gresham v. Azar,* 363 F. Supp. 3d 165 (D.D.C. 2019).

Racial health disparities persist in the United States for a myriad of reasons, and Black people in this country continue to have worse health outcome measures than white people. As the Department recognizes in its Proposed Rule, "[d]iscrimination in health programs and

[1] Submitted at https://www.regulations.gov/commenton/HHS-OS-2022-0012-0001.

activities can lead to disparate health outcomes and adverse differences in access to care."[2] Equal access to health coverage and services, free from discrimination, is vital for communities of color.

The Proposed Rule accomplishes much to fully implement Section 1557. Below, we provide support for certain key provisions as well as recommendations that we believe would enable stronger enforcement to ensure the anti-discrimination goals of Section 1557 are fully realized in this rulemaking:

- In order to identify systemic discrimination, the Department should mandate the collection of minimum disaggregated data across health programs and activities.
- The Department rightly asserts the fundamental need to combat systemic discriminatory barriers to health equity, clarifies Section 1557's enforcement mechanisms, and provides examples of prevalent forms of systemic discrimination which occur today.
- The Department should more explicitly list intersectional discrimination as prohibited conduct and explain the applicable procedures for administrative enforcement of such claims.

In short, we strongly support the Proposed Rule and recommend it be finalized and implemented, with consideration given to the following recommendations.

I. THE FINAL RULE SHOULD ESTABLISH A CIVIL RIGHTS DATA COLLECTION REQUIREMENT THAT ADDRESSES RACIAL HEALTH DISPARITIES

A. Voluntary and Inadequate Demographic Data Collection Inhibits Civil Rights Enforcement

Recommendation: The Final Rule should include a mandatory data collection provision.

We are pleased the Proposed Rule recognizes that civil rights data collection plays a "vital role" in civil rights compliance.[3] However, we strongly oppose the Department's decision to exclude a data collection provision in the Proposed Rule, given its own recognition "that such data remain largely uncollected for many demographic subgroups."[4] Comprehensive demographic data collection is key to addressing the various and many ways systemic racism in health care disparately impacts communities of color and drives worse health outcomes. Demographic data collection is the foundation to better understanding and addressing racial health disparities, especially for people living at the intersections of multiple identities. Indeed, "vulnerable communities aren't all vulnerable in the same way."[5]

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[2] "Nondiscrimination in Health Programs or Activities," 87 Fed. Reg. 47831 (Aug. 3, 2022), RIN 0945-AA17.
[3] *Id.* at 47856.
[4] *Id.*
[5] Service, Kelly. "'Huge Hole' in COVID-19 Testing Data Makes It Harder to Study Racial Disparities." *Science Insider*, 10 July 2020, https://www.science.org/content/article/huge-hole-covid-19-testing-data-makes-it-harder-study-racial-disparities (accessed 10 Dec. 2021).

As such, data that promotes equity in health care must encompass race and ethnicity disaggregated into subgroups, rather than consolidated into broad categories that do not distinguish between diverse populations who experience unique and varying social determinants of health. Equitable data also requires the collection of primary language, disability status, housing status, pregnancy status, employment status and type, insurance status, and sexual orientation and gender identity metrics. Equitable data must also track the distribution and utilization of various health care resources. Such resources include screening, testing, and treatment for a variety of illnesses and diseases that disproportionately afflict communities of color and other systemically marginalized populations, yet are often inaccessible to these very groups. Health care data that do not track these vital demographic metrics are incomplete and restrict efforts to deliver health care resources that address the full impact of disease incident, including COVID-19, on those living at the intersection of multiple marginalized identities.

Beyond rooting out inequities in health care, data collection is also a critical civil rights enforcement tool. As described by the Department of Justice:

> Civil rights data collection is the cornerstone of effective Title VI enforcement. The importance of diligently gathered and thoroughly analyzed data cannot be overstated. It is indispensable to the investigatory process in assessing allegations of discrimination and can form the basis for initiating compliance reviews focusing on particular issues or systemic problems that require technical assistance, policy guidance, litigation, or other enforcement mechanisms to remedy discrimination. It is also an effective mechanism to support agency oversight and ensure that discrimination does not recur.[6]

Despite the critical importance of data collection in health care, existing efforts are entirely insufficient to meet the goals of Section 1557 or the Affordable Care Act, broadly. There is widespread agreement that "[e]xisting racial misclassifications in public health data are ubiquitous" and, yet, "it is impossible to fully understand the health implications of racism—or any other difference in the way people are treated—when the populations most at risk have been grossly miscategorized across risk categories."[7] Demographic data collection thus plays an outsized role in effectuating Section 1557's goals of reducing health disparities by prohibiting discrimination in health programs and activities.

In view of this, the Department's proposal to merely collect data through sub-regulatory compliance reporting mechanisms under 45 C.F.R. 80.6(b) falls far short of ensuring consistent and comprehensive data collection. As described by the Sixth Circuit, 45 C.F.R. 80.6(b), which remains the same today, does not obligate the Department to collect data at all:

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[6] "Frequently Asked Questions- Data Collection." *The United States Department of Justice*, 28 Apr. 2021, https://www.justice.gov/crt/frequently-asked-questions-data-collection.

[7] Holtzman, Geoffrey S., et al. "The Racial Data Gap: Lack of Racial Data as a Barrier to Overcoming Structural Racism." *The American Journal of Bioethics*, vol. 22, no. 3, 2022, pp. 39–42, https://doi.org/10.1080/15265161.2022.2027562.

> 45 C.F.R. § 80.6(b) does not mandate that HHS act as an information clearinghouse, collecting racial and ethnic data to provide statistics useful to plaintiffs. To the contrary, Title VI mandates that as one of the mechanisms to enforce the Act, HHS shall require recipients to submit compliance reports as the responsible Department official "may determine to be necessary to enable him to ascertain whether the recipient has complied or is complying with this part"—in other words, at the agency's discretion.

Madison-Hughes v. Shalala, 80 F.3d 1121, 1126 (6th Cir. 1996). In sum, data collection through 45 C.F.R. 80.6(b) compliance reporting is entirely optional, "rather than mandating specific requirements." *Id*. We note that this leaves data collection efforts vulnerable to future administrations that may not prioritize data collection or may even be hostile towards it.

Moreover, optional data collection has proven ineffective throughout the Department and its agencies. In 1984, Margaret M. Heckler,[8] then-Secretary of HHS, established the Task Force on Black and Minority Health ("Minority Health Task Force" or "Task Force") to address "a continuing disparity in the burden of death and illness experienced by Blacks and other minority Americans."[9] The Task Force released a report the next year emphasizing the fundamental need to "[i]mprove data collection and interpretation of data regarding specific minority groups,"[10] stating:

> Reliable data are central to measuring progress in public health, and are the key to assessing the current health status of the Nation and measuring health status trends; recognizing both sources of and solutions to problems; identifying health disparities between segments of the population; and targeting efforts directly to specific needs.[11]

Thus, as long ago as 1985, the federal government explicitly acknowledged that detailed race/ethnicity demographic data is critical to "program planning, implementing, and monitoring" racial health disparities and health outcomes.[12] Yet, almost 40 years later, there remains a dearth of health care data reflecting diverse populations and people living at the intersections of multiple identities. Worse, our health care system remains replete with stark disparities, as people of color and other systemically marginalized populations continue to die at about twice the rate of white people from COVID-19.[13]

And, during the greatest public health crisis in a century, efforts to collect even minimal demographic data relating to the pandemic have been inadequate. More than two years into the pandemic, the CDC is still missing federal race and ethnicity data for 37 percent of all COVID-

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[8] *Heckler, Margaret M.* US House of Representatives: History, Art & Archives, https://history.house.gov/People/Detail/14824 (accessed 10 Dec. 2021).
[9] HHS, *Report of the Secretary's Task Force on Black and Minority Health*, ix.
[10] *Id.* at 211.
[11] *Id.* at 31.
[12] *Id.*
[13] "Risk for COVID-19 Infection, Hospitalization, and Death by Race/Ethnicity." *Centers for Disease Control and Prevention*, https://www.cdc.gov/coronavirus/2019-ncov/covid-data/investigations-discovery/hospitalization-death-by-race-ethnicity.html (accessed 9 Dec. 2021).

19 cases as of April 30, 2022, although there was age and sex data for nearly all cases.[14] Likewise, the CDC lacks race and ethnicity data for approximately 25 percent of people who have received at least one dose of the COVID-19 vaccine.[15] This data gap endures despite legislation mandating the collection of COVID-19 race and ethnicity data, administrative support from the CDC for data collection efforts,[16] as well as an Executive Order, titled *Ensuring an Equitable Pandemic Response and Recovery*, issued by President Biden.[17] That Executive Order stressed that "[t]he lack of complete data, disaggregated by race and ethnicity, on COVID-19 infection, hospitalization, and mortality rates, as well as underlying health and social vulnerabilities, has further hampered efforts to ensure an equitable pandemic response."[18] Yet, almost two years later, the data gap regarding race and ethnicity for vaccinations and cases remains nearly stagnant.

Given the decades-long struggle to collect minimal demographic data outlined above, the Department must take decisive action and include a mandatory data collection provision in this rulemaking. The importance of doing so cannot be overstated. In addition to the reasons discussed above, including a data collection mandate in this rule would establish demographic data collection as a clear component of civil rights enforcement and create an unambiguous requirement for covered entities. The Department's mandate is clear—enforce the anti-discrimination provision of the Affordable Care Act. It simply cannot effectuate this goal without demographic data and as such should be required under the Final Rule.

B. The Department Should Establish a National Set of Data Collection Measures in Order to Effectively Enforce Section 1557

Recommendation: The Department should establish minimum data collection requirements in the Final Rule that:

- include the collection of minimum disaggregated race, ethnicity, disability, and primary language data in line with the 2011 HHS Data Standards;
- include the collection of sex, sexual orientation, and gender identity data which mirrors Version 2 of the United States Core Data for Interoperability;
- align with patient outcome metrics; and
- reflect the role the Social Determinants of Health ("SDOH") play in the accessibility of health care.

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[14] "COVID-19 Weekly Cases and Deaths per 100,000 Population by Age, Race/Ethnicity, and Sex." *Centers for Disease Control and Prevention*, Centers for Disease Control and Prevention, https://covid.cdc.gov/covid-data-tracker/#demographicsovertime (accessed 2 May 2022).
[15] "Demographic Characteristics of People Receiving COVID-19 Vaccinations in the United States." *Centers for Disease Control and Prevention*, Centers for Disease Control and Prevention, https://covid.cdc.gov/covid-data-tracker/#vaccination-demographic (accessed 2May 2022).
[16] "Demographic Trends of COVID-19 Cases and Deaths in the US Reported to CDC." *Centers for Disease Control and Prevention*, Centers for Disease Control and Prevention, https://covid.cdc.gov/covid-data-tracker/#demographics (accessed 10 Dec. 2021).
[17] Executive Order. No. 13995, 2021, https://www.federalregister.gov/documents/2021/01/26/2021-01852/ensuring-an-equitable-pandemic-response-and-recovery.
[18] *Id.*

The COVID-19 pandemic represents the clearest picture of data collection in health care today and the urgent need for standardized civil rights data collection. A 50-state survey conducted by the Lawyers' Committee in 2021 analyzed the types of data published by states and found that no two states published the same COVID-19 demographic data.[19] That survey found that no state consistently published any COVID-19 data disaggregated by Latinx subgroups, and only one state (Hawaii) disaggregated data by Asian subgroups.[20] In fact, some states, like West Virginia and Florida, collected racial data for COVID-19 cases for only the subgroups "white," "Black," "other," and "unknown"—all Asian, Pacific Islander, and Native Hawaiian people are counted as "other."[21] Likewise, the District of Columbia used over-aggregated race categories on its COVID-19 vaccine dashboard.[22,] And Hawaii, North Dakota, and West Virginia did not collect any ethnicity data for COVID-19 cases.[23] That states vary widely in their COVID-19 data collection practices is unsurprising. Lack of guidance from the federal government regarding data collection and reporting at the pandemic's onset meant states were left to develop their own data collection processes and tools. And unfortunately, just as the Minority Health Task Force found in 1985, "the lack of common practices among the [s]tates in recording ethnicity identifiers in their reported data" has resulted in a data shortfall.[24] Including a standardized data set in the Final Rule will remedy this longstanding problem.

Moreover, current federal and state demographic data standards do not reflect the needs for such information that have been acknowledged by the federal government for almost 40 years. Three of the federal government's main COVID-19 data collection channels—the CDC's Case Report Form/Surveillance Worksheet, the CDC's COVID-19 Vaccination Program, and V-safe, a smartphone app for recording adverse vaccine events—ask only for race/ethnicity demographic data using the outdated 1997 OMB Standards.[25] These channels also largely ignore

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[19] Sharma, Monica. "Lawyers' Committee for Civil Rights Under Law 50-State Survey to Determine State Data Collection Methods Related to COVID-19." Mar. 2021.

[20] *Id.*; "Which Racial and Ethnic Groups Have Been Most Affected?" *State of Hawaii Department of Health*, https://health.hawaii.gov/coronavirusdisease2019/current-situation-in-hawaii/#race (accessed March 2021).

[21] "West Virginia COVID-19." *West Virginia Department of Health and Human Resources*, https://dhhr.wv.gov/COVID-19/Pages/default.aspx (accessed March 2021); *Florida's COVID-19 Data and Surveillance Dashboard*. Florida Department of Health Division of Disease Control and Health Protection, https://www.arcgis.com/apps/dashboards/2c9ba0a8d6374555bc4bc620be916bae (accessed March 2021).

[22] Racial categories for vaccinations in D.C. include: Asian, White, Black, American Indian or Alaska Native, and Unknown & Other. "Vaccination Data." *Government of the District of Columbia*, https://coronavirus.dc.gov/data/vaccination. .

[23] *Hawaii COVID-19 Data–Race*, https://health.hawaii.gov/coronavirusdisease2019/current-situation-in-hawaii/#race (accessed Sept. 2021); "West Virginia COVID-19." *West Virginia Department of Health and Human Resources*, https://dhhr.wv.gov/COVID-19/Pages/default.aspx (accessed Sept. 2021); "North Dakota Coronavirus Cases." *North Dakota Department of Health*, www.health.nd.gov/diseases-conditions/coronavirus/north-dakota-coronavirus-cases (accessed Sept. 2021).

[24] HHS, *Report of the Secretary's Task Force on Black and Minority Health*, 33.

[25] "Human Infection with 2019 Novel Coronavirus Case Report Form." *Centers for Disease Control and Prevention*, US Department of Health and Human Services, www.cdc.gov/coronavirus/2019-ncov/downloads/pui-form.pdf; "Human Infection with Coronavirus Disease 2019 (COVID-19) Surveillance Worksheet." *Centers for Disease Control and Prevention*, US Department of Health and Human Services, https://www.cdc.gov/ncird/surveillance/downloads/COVID-19-Surveillance-Worksheet-508.pdf; "COVID-19 Vaccination Provider Requirements and Support." *Centers for Disease Control and Prevention*, US Department of Health and Human Services, 30 Apr. 2021, www.cdc.gov/vaccines/covid-19/vaccination-provider-support.html; "V-Safe Active Surveillance for COVID-19 Vaccine Safety." *Centers for Disease Control and Prevention*, US Department of Health and Human Services, 28 Jan. 2021, www.cdc.gov/vaccinesafety/pdf/V-safe-Protocol-508.pdf.

two other categories of demographic data required under Section 4302 of the Affordable Care Act—primary language and disability status.[26] Neither the CDC nor the majority of state public health jurisdictions and health care systems endeavored to collect broader data that reflects the role the Social Determinants of Health ("SDOH") play in the accessibility of health care.

The Department has vast authority to establish standardized civil rights data collection across health programs and activities and improve data collection efforts by covered entities. In addition to the Department's authority to collect data on protected classes under the enumerated statutes, other provisions in the Affordable Care Act authorize the collection of "any other demographic data as deemed appropriate by the Secretary regarding health disparities."[27] The Final Rule must therefore mandate covered entities to collect minimum disaggregated race, ethnicity, disability, and primary language data that mirrors the 2011 HHS Data Standards.[28] The 2011 HHS Data Standards disaggregate the "Asian," "Native Hawaiian or Other Pacific Islander," and "Hispanic or Latino" categories into subgroups, thus providing more detailed information about the distinctive health outcomes of subgroups within these massive populations.[29] The Department must also mandate the collection of sex, sexual orientation, and gender identity data which, at minimum, mirrors Version 2 of the United States Core Data for Interoperability. That standard requires the collection of data that aligns with the Department's definition of "sex" in the Proposed Rule.

We also recommend that any data collection requirement align with patient outcome metrics. Racial health disparities are directly attributable to discriminatory policies and practices that disparately impact patients of color. Linking patient outcome metrics with demographic data collection is thus critical to identifying systemic causes of health inequities and disparities. Similarly, the Department should also recommend covered entities collect data relating to the SDOH. This aligns with the Department's own established goals. For example, the Department conducted a scoping review to identify SDOH that are risk factors for, or associated with outcomes of, COVID-19 and reported that the resulting evidence calls for the standardization of SDOH data across health care, public health, and research.[30] Additionally, in March 2022, the Department specifically identified integrating social determinants of health data into surveillance systems, electronic health records, clinical decision supports, and other data collection points in order to "[i]mprove data collection and conduct evaluations to understand the drivers for inequities in health outcomes, social well-being, and economic resilience."[31]

The inclusion of nationalized minimum data collection standards in this rulemaking effort will represent a serious effort to rectify the vast inconsistencies in data collection across health

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[26] *Id.*
[27] 42 U.S.C. § 3101.
[28] "HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status." *ASPE*, https://aspe.hhs.gov/reports/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-disability-0.
[29] *Id.*
[30] Kim, Katherine K. et al.,"Scoping Review Report: Data Elements for Research on the Role of Social Determinants of Health in Coronavirus Disease 2019 Infection and Outcomes in the U.S." *ASPE*, https://aspe.hhs.gov/reports/scoping-review-report-sdoh-covid-19.
[31]Assistant Secretary for Planning and Evaluation (ASPE). "Strategic Plan FY 2022 – 2026." *HHS.gov*, 25 Mar. 2022, https://www.hhs.gov/about/strategic-plan/2022-2026/index.html.

care systems. The Department should codify, through regulation, a civil rights data collection requirement in order to sufficiently address the gaps in demographic data collection in health programs and activities.

II. THE FINAL RULE SHOULD ENSURE ROBUST ENFORCEMENT OF SECTION 1557 REMEDIES TO ADEQUATELY COMBAT SYSTEMIC RACISM IN HEALTH CARE

Given the enormity of discriminatory conduct in health care, Section 1557 requires rigorous enforcement in order to ensure communities of color and other marginalized groups can access quality health care. The Department is correct that eliminating discrimination in health programs and activities requires "robust implementation and enforcement of Section 1557."[32] We are therefore pleased the Proposed Rule provides concrete tools for enforcement, consistent with existing law and the clear, unambiguous intent of Section 1557.

A. The Proposed Rule Appropriately Applies a Common Standard for Administrative Enforcement Actions Under Section 1557

We commend the Department's proposed adoption of clear and uniform procedures for administrative enforcement actions under proposed Section 92.303(a)-(b). Doing so will reduce confusion and uncertainty, and promote efficiency, in the administrative enforcement of claims of discrimination.

Recommendation: The Final Rule should provide clear procedures for the administrative enforcement of intersectional claims of discrimination, e.g., on the basis of race and age.

B. The Department's Enforcement of Disparate Impact Complaints is Imperative to Meet the Goals of Section 1557

The Department asks whether to include provisions prohibiting the use of "criteria and methods of administration" and facility site selection with "the effect of" discriminating on the basis of sex, as did the 2016 rule, and whether any such provisions should be expanded to prohibit disparate impacts as to the other prohibited characteristics.[33] The Proposed Rule does not include such provisions, but rather references the implementing regulations of the underlying statutes. As the Proposed Rule notes, the implementing regulations of Title VI, Section 504, and the Age Act contain provisions prohibiting the use of "criteria and methods of administration" and facility site selection with "the effect of" discriminating on the basis of race, color, national origin, disability, and age.

It is critical that OCR continue to exercise its authority to enforce disparate impact claims. The United States health care system is awash in examples of systemic racism. Health equity scholars are clear that addressing racial health disparities requires an "intentional and sustained focus" on systemic discrimination:

[32] *Id.*
[33] 87 Fed. Reg. 47860 (Aug. 3, 2022).

> As long as structural racism continues to shape health care policy, racial and ethnic minority populations will suffer from inequitable access to high-quality health care. Existing reforms have not remedied this problem because the eradication of structural racism in health care policy has not been a primary goal.[34]

As scholars have recognized since the civil rights movement, "while [] individual acts [of racism] are important, they constitute a tiny snapshot of the larger institutional racism picture."[35] Indeed, patients are less likely to experience more overt forms of racism, as race discrimination within health care systems manifests in more subtle forms today.[36] Barriers to health care today more closely resemble disparate impact than disparate treatment.[37] Section 1557 cannot address race discrimination in health care without administrative enforcement of disparate impact claims.

C. The Rule Properly Identifies Examples of Systemic Discrimination Through the Use of Clinical Algorithms, Crisis Standards of Care, and Narrow Networks

We offer strong support for Proposed Section 92.210, which 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.[38] This provision is critical in addressing one of the most prevalent forms of discrimination in health care today. Many diagnostic algorithms used by physicians include race and guide decisions in ways that may direct more attention or resources to white patients than to members of racial and ethnic minorities.[39]

The Department recognizes the risks that certain protected classes, specifically Black patients and patients with disabilities, are denied health care through the use of Crisis Standards of Care, and specifically requests comment on the topic of racial inequities in Crisis Standards of Care. Crisis Standards of Care often reflect a bias against disabled people, people of color, and older adults.[40] They typically prioritize care towards 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 presumed to require

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[34] Yearby, Ruqaiijah, et al. "Structural Racism in Historical and Modern US Health Care Policy: Health Affairs Journal." *Health Affairs*, 1 Feb. 2022, https://www.healthaffairs.org/doi/10.1377/hlthaff.2021.01466.
[35] Feagin, Joe, and Zinobia Bennefield. "Systemic Racism and U.S. Health Care." *Social Science & Medicine*, vol. 103, 2014, pp. 7–14., https://doi.org/10.1016/j.socscimed.2013.09.006 (citing Ture, K., & Hamilton, C. (1967). Black power. New York: Random House.).
[36] Fauci, Cara A. "Racism and Health Care in America: Legal Responses to Racial Disparities in the Allocation of Kidneys." *Boston College Third World Journal*, vol. 21, no. 1, Jan. 2001, pp. 35–67.
[37] Chandra, Amitabh, et al. "Challenges to Reducing Discrimination and Health Inequity through Existing Civil Rights Laws." *Health Affairs (Project Hope)*, U.S. National Library of Medicine, 1 June 2017, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5654529/.
[38] *Id.*
[39] Vyas, Darshali A., et al. "Hidden in Plain Sight — Reconsidering the Use of Race Correction in Clinical Algorithms." *New England Journal of Medicine*, vol. 383, no. 9, 2020, pp. 874–882., https://doi.org/10.1056/nejmms2004740.
[40] Center for Public Representation, *Examining How Crisis Standards of Care May Lead to Intersectional Medical Discrimination Against COVID-19 Patients*, p. 6, https://www.centerforpublicrep.org/wp-content/uploads/FINAL-Intersectional-Guide-Crisis-Care-PDF.pdf.

greater resources to survive the acute episode of illness.[41] Disabled people of color may also be disproportionately denied life-saving care when Crisis Standards of Care are in effect. "Aside from the public health issues that most racial/ethnic minorities face, minorities with disabilities experience additional disparities in health, prejudice, discrimination, economic barriers, and difficulties accessing care as a result of their disability—in effect, they face a "double burden."[42] Similarly, simultaneous oppression—"areas in which the experiences of Blacks/African Americans with disabilities result in a distinct form of oppression that entails limited or no individuality and disability identity, resource discrimination, and isolation within the Black/African American community and family"—often leads to resources not being allocated to devalued individuals.[43] The higher incidence of health problems makes it more likely that disabled people of color will be denied treatment if medical treatment is rationed using discriminatory crisis standards of care.

Recommendation: We recommend the Final Rule state that Crisis Standards of Care should be evaluated for any disparate effects on protected classes of patients, and modifications made as needed to promote equitable resource allocation.

The Proposed Rule also appropriately notes that certain health insurance plans may violate Section 1557 by creating "narrow networks," which restrict the availability of certain health care providers in an insurance network. Narrow networks raise discrimination concerns, as they are disproportionately comprised of people of color, and also tend to exclude hospitals that serve greater portions of Black patients. Studies have shown that people living with low incomes without employer-sponsored health insurance[44] and the uninsured[45] are more likely to select health insurance plans with narrow networks.[46] Another study of insurance plans across 37 states showed that Hispanic people were "significantly more likely to be in a narrow-network plan than in a plan with a broad network, while the opposite was true for non-Hispanic white people," and that enrollment disparities also existed for Black people.[47]

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[41] *Id.*

[42] HHS Advisory Committee on Minority Health, *Assuring Health Equity for Minority Persons with Disabilities: A Statement of Principles and Recommendations* (July 2011) p. 11, https://minorityhealth.hhs.gov/assets/pdf/checked/1/acmhhealthdisparitiesreport.pdf.

[43] *Id.*

[44] Forty-five percent of Black workers did not have employer-sponsored health insurance in 2019. Office of Health Policy, *Health Insurance Coverage and Access to Care Among Black Americans: Recent Trends and Key Challenges*, ASSISTANT SEC'Y FOR PLAN. AND EVALUATION 1, 7 (Feb. 22, 2022), https://aspe.hhs.gov/sites/default/files/documents/08307d793263d5069fdd6504385e22f8/black-americans-coverages-access-ib.pdf.

[45] Kaiser Family Foundation. "Uninsured Rates for the Nonelderly by Race/Ethnicity." KFF, 23 Oct. 2020, https://www.kff.org/uninsured/state-indicator/nonelderly-uninsured-rate-by-raceethnicity/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D#

[46] Blake, Valarie. "Narrow Networks, the Very Sick, and the Patient Protection and Affordable Care Act: Recalling the Purpose of Health Insurance and Reform." *Minnesota Journal of Law, Science, & Technology*, vol. 16, no. 1, ser. 4, 2015, p. 86.

[47] Sen, Aditi P., et al. "Most Marketplace Plans Included at least 25 Percent of Local-Area Physicians, But Enrollment Disparities Remained." *Health Affairs*, vol. 36, no. 9, 2017, p. 1620.

Moreover, narrow networks regularly exclude acute care and academic hospitals,[48] which may disparately impact people of color. These hospitals are more likely to serve a higher percentage of low-income patients.[49] Notably, analyses of data on inpatient hospitalizations in the period 2012–14 for Medicare beneficiaries ages 65 and older revealed that academic hospitals serve larger proportions of Black beneficiaries compared to non-teaching hospitals.[50] A national study also found that people treated at academic hospitals had lower mortality risk compared to those treated at nonteaching hospitals.[51] Other studies have found that cancer treatment centers are regularly excluded from insurance plans on exchange networks,[52] and that these centers are often underutilized by Hispanic and Asian groups, despite better treatment outcomes.[53] As a result, people of color, who are likely to be overrepresented in patient populations insured under a plan with a narrow network, may have less access to a range of specialized providers and treatments that can result in life-saving care.

Recommendation: The Final Rule should highlight the discriminatory impacts of narrow networks including those that exclude hospitals more likely to serve Black and other patients of color.

These few examples demonstrate the ways in which systemic discrimination occurs today and the essential need for the Department to exercise its full enforcement authority to effectuate the purpose of Section 1557.

D. The Proposed Rule Correctly Recognizes that Section 1557 Creates a Private Right of Action.

It is well-established that Section 1557 creates a new private right of action. *See Southeastern Pennsylvania v. Gilead*, 102 F. Supp. 3d 688, 698-99 (E.D. Pa. 2015) (noting that "Section 1557 does create a new private right under the Affordable Care Act . . ."); *Briscoe v. Health Care Serv. Corp.*, 281 F. Supp. 3d 725, 738 (N.D. Ill. 2017) ("this Court agrees with other district courts that § 1557 provides a private right of action"); *York v. Wellmark, Inc.*, No. 4:16-cv-00627-RGE-CFB, at *15-16 (S.D. Iowa Sep. 6, 2017) ("the Court agrees with other district courts that § 1557 provides a private right of action.").

The recognition of a private right of action is particularly important given that the Office of Civil Rights is severely under-resourced and can only challenge a fraction of complaints it

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[48] Blake, "Narrow Networks, the Very Sick, and the Patient Protection and Affordable Care Act," supra note 45, at 85.
[49] *Id.*
[50] Burke, Laura, et al. "Do Academic Medical Centers Disproportionately Benefit the Sickest Patients?" *Health Affairs*, vol. 37, no. 6, 2018, pp. 864-872, https://doi.org/10.1277/hlthaff.2017.1250.
[51] *Id.* at 867
[52] Schleicher SM, Mullangi S, Feeley TW. "Effects of Narrow Networks on Access to High-Quality Cancer Care" JAMA Oncol. 2016;2(4):427–428. doi:10.1001/jamaoncol.2015.6125; Yasaitis, Laura, et al. "Relation Between Narrow Networks and Providers of Cancer Care." *Journal of Clinical Oncology*, vol. 35, no. 27, 5 July 2017, pp. 3131-3135., https://doi.org/10.1200/jco.2017.73.2040.
[53] Huang, Lyen C. et al. "What Factors Influence Minority Use of National Cancer Institute-Designated Cancer Centers?" *National Library of Medicine*, vol. 120, no. 3, 21 Oct. 2013, pp. 399-407, https://doi.org/10.1002/cncr.28413.

receives.[54] Scholars note that "private parties play a more important role in enforcing regulatory law in the U.S. legal system than in other advanced economies," and that private parties "bring significant additional resources to the task of enforcing public law . . . [as] state and federal agencies are chronically under-resourced and overworked."[55] Indeed, since Fiscal Year 2016, civil rights case receipts have increased by 252 percent, leaving the Department's Office of Civil Rights with a backlog of complaints.[56] We therefore offer strong support for the Proposed Rule's clarification that a private right of action exists for all claims of discrimination under Section 1557, as judicial enforcement is necessary to protect patients and other beneficiaries from discriminatory conduct.[57]

III. DISCRIMINATION IN HEALTH CARE IS OFTEN INTERSECTIONAL AND THE FINAL RULE SHOULD MORE DIRECTLY ADDRESS THIS REALITY

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. The Proposed Rule proscribes many forms of discrimination that amplify the impacts of racism and subject people to dual discrimination. For example, the Proposed Rule seeks to eliminate discrimination against Limited English Proficient (LEP) individuals and people living with disabilities — groups that are predominately comprised of people of color. Likewise, Section 1557 proscribes sex discrimination in health care and the Proposed Rule clarifies that "sex discrimination" includes discrimination on the basis of sexual orientation and gender identity. Both cisgender women of color and LGBTQI+ people of color face racism in health care that is amplified by their gender, sexual orientation, or gender identity. As discussed further below, the Proposed Rule restricts discriminatory conduct against these groups, thus improving health care access for people of color with multiple systemically marginalized identities.

Because no person inhabits a singular identity, it is often impossible to determine whether an individual experiences discrimination based on one identity or another. It is often the case that race intensifies other forms of discrimination, such as sex, gender identity, and disability status. This dual-discrimination often leads to the provision of worse health care and services. For example, transgender people of color face significant barriers to health care access. As noted in a recent report by the Centers for American Progress, transgender people of color more frequently

[54] Chandra, Amitabh, et al. "Challenges to Reducing Discrimination and Health Inequity through Existing Civil Rights Laws." *Health Affairs (Project Hope)*, U.S. National Library of Medicine, 1 June 2017, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5654529/.
[55] Sant'Ambrogio, Michael. "Private Enforcement in Administrative Courts." *Vanderbilt Law Review*, vol. 72, no. 2, March 2019, pp. 425-500, https://scholarship.law.vanderbilt.edu/vlr/vol72/iss2/2
[56] U.S. Department of Health and Human Services. "HHS FY 2023 Budget in Brief." U.S. Department of Health and Human Services, 28 Mar. 2022, https://www.hhs.gov/about/budget/fy2023/index.html
[57] 87 Fed. Reg. 47885 (Aug. 3, 2022).

experience denial of care and medical abuse than white transgender people.[58] That report further notes that transphobia is often inseparable from racism and sexism in the medical system.[59] Moreover, 65 percent of transgender people of color report experiencing some form of discrimination, and 46 percent of transgender people report having their health insurance deny gender affirming care.[60]

Moreover, according to one study, a "substantial number of Asian Americans reported encountering racial discrimination and possessing limited English proficiency."[61] Another study revealed that 65 percent of patients in the study indicated that they have felt discriminated against by health care staff because of their Hispanic ethnicity or LEP.[62] Likewise, disability discrimination often involves intersectional claims, as Black people in the United States suffer from disability rates that are up to 2.5 times greater than white people.[63] Scholars note that "the single-issue focus on disability is erasing the complex experiences that multiply marginalized disabled people experience, creating a revolving door of inequities that are compounded in disabled communities of color."[64]

Similarly, Black women face significant disparities in health care and outcomes including shorter life expectancies, chronic conditions, such as anemia, cardiovascular disease (CVD), and obesity, and higher rates of maternal mortality.[65] In order to prioritize the preventable loss of life, these disparities in health care need to be addressed through an intersectional approach because "the experiences of persons occupying the marginalized spaces of gender and race, such as Black women, 'cannot be captured wholly by looking at race or gender dimensions separately.'"[66]

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[58] Medina, Caroline, et al. "Protecting and Advancing Health Care for Transgender Adult Communities." *American Progress,* 18 Aug. 2021, https://www.americanprogress.org/article/protecting-advancing-health-care-transgender-adult-communities/

[59] *Id.*

[60] Woodcome, Tricia. "New Data and Analysis Illustrate Disparities in Health Status and Access to Care for Transgender Adults." *American Progress,* 18 Aug. 2021, https://www.americanprogress.org/press/release-new-data-analysis-illustrate-disparities-health-status-access-care-transgender-adults/

[61] 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

[62] Calo, William A., et al. "Experiences of Latinos with Limited English Proficiency with Patient Registration Systems and their Interactions with Clinic Front Office Staff: an Exploratory Study to Inform Community-Based Translational Research in North Carolina." *BMC Health Services Research,* vol. 15, no. 1, 23 Dec. 2015, https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-015-1235-z

[63] Ross, Martha et al. "Disability rates among working-age adults are shaped by race, place, and education." Brookings, 15 May 2018, https://www.brookings.edu/blog/the-avenue/2018/05/15/disability-rates-among-working-age-adults-are-shaped-by-race-place-and-education/#:~:text=In%20most%20places%2C%20as%20at,up%20to%202.5%20times%20greater.

[64] Natalie M. Chin, Centering Disability Justice, 71 Syracuse L. Rev. 683, 684 (2021).

[65] Chinn, Juanita J, et al. "Health Equity among Black Women in the United States." *Journal of Women's Health (2002)*, Mary Ann Liebert, Inc., Publishers, Feb. 2021, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8020496/.

[66] Patterson, Evelyn J., et al. "Gendered Racism on the Body: An Intersectional Approach to Maternal Mortality in the United States." *Population Research and Policy Review*, vol. 41, no. 3, 2022, p. 1263, https://doi.org/10.1007/s11113-021-09691-2.

Ultimately, health outcomes do not occur independent of social conditions, but rather reflect structural inequities, which people with intersecting identities experience in different ways. The Department must adequately account for this reality in the Final Rule.

Recommendation: The Final Rule should explicitly prohibit intersectional discrimination in Section 92.101, clarifying that section also prohibits discrimination based on the intersection of two or more protected bases (e.g., race and sex). In addition, as stated in section II(A) above, the Final Rule should provide clear procedures for the administrative enforcement of intersectional claims.

IV. CONCLUSION

The Proposed Rule is a significant step towards addressing discrimination against people of color and other systemically marginalized groups. It should be finalized with serious consideration given to the issues raised above.

Thank you for the opportunity to submit comments on the proposed rule, which the Lawyers' Committee strongly supports. Please do not hesitate to contact Kathryn Youker, Director, Economic Justice Project, at kyouker@lawyerscommittee.org, if you have any questions about these comments.

Sincerely,

Lawyers' Committee for Civil Rights Under Law

By: /s/ Kathryn J. Youker
Kathryn J. Youker
Economic Justice Project Director