CLASP
The Center for Law and Social Policy

October 3, 2022

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

Re: RIN 0945-AA17
Nondiscrimination in Health Programs and Activities

Dear Acting Director Fontes Rainer:

The Center for Law and Social Policy (CLASP) appreciates the opportunity to comment on the Department of Health and Human Services' Office for Civil Rights (OCR) proposed rule, Nondiscrimination in Health Programs and Activities (hereinafter "2022 Proposed Rule") CLASP is a national, nonpartisan anti-poverty nonprofit advancing policy solutions for low-income people. CLASP strives to reduce poverty, promote economic security and advance racial equity. We work at federal, state, and local levels, supporting policy and practice that makes a different in the lives of people living in conditions of poverty.

We believe that quality, affordable healthcare is critical for everyone, but for many people, particularly those who are low-income, medical care often remains inaccessible. Section 1557 prohibits discrimination on the basis of race, color, national origin, sex, age, and disability. As an organization that is committed to upholding the civil rights of all persons – and particularly for persons with low-incomes and people of color- we strongly support the NPRM provisions which seek to protect individuals who are limited English proficient, LGBTQ+ persons, persons with disabilities and chronic conditions, and persons needing reproductive health services. The final rule must not only provide protections for each protected class covered, but the intersection of those protections.

The U.S. medical system, including policies and systems, was created to treat people of color, and in particular Black people, differently. People with low incomes are particularly vulnerable to discrimination because of intersecting identities and barriers to access health services. Unfortunately today, the differences in care have not been completely eradicated from our medical system; instead, discrimination exists in financing, data, the quality of care, and treatment.[1] Today, biases in health care still exist; with some health professionals not believing Black people when they are in pain.[2] Additionally, racist policies

(i.e. redlining, employment discrimination, etc.) have contributed to the racial wealth gap.[3,4,5] As a result of systemic racism and discrimination, 23.8% of people living in poverty are Black,[6] and about one-third of Black people use Medicaid for health coverage.[7] Many people of color in the United States live under the anti-Blackness paradigm, whether by experiencing or perpetuating racism.[8]

Section 1557 of the Affordable Care Act is a significant step toward rectifying centuries of policies and practices that have created worse health outcomes for communities of color, individuals with disabilities, women of color, LGBTQI+ people, Limited English Proficient (LEP) individuals, older adults and children, and other systemically marginalized groups.

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 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 racism and other forms of discrimination in health care. First, the Proposed Rule addresses various forms of discrimination that disproportionately affect communities of color, including on the basis of disability status, national origin, and sex. Second, the Proposed Rule addresses systemic discrimination, including policies and practices that harm people of color. Finally, the Proposed Rule calls for vast enforcement authority across all segments of the health care system and related activities — ensuring Section 1557's prohibition against race discrimination is adhered to across the United States.

Ultimately, this Proposed Rule is a landmark regulatory effort to address discrimination and racism in health care. The Proposed Rule should be finalized, and the issues and recommendations raised below should be strongly considered by the Department.

Our comments on the provisions of the 2022 Proposed Rule are as follows.

SUBPART A – GENERAL PROVISIONS

Application (§ 92.2)

We strongly support the 2022 Proposed Rule which restores regulations recognizing § 1557's applicability to federal health programs like Medicaid. The rule further clarifies that § 1557 applies to short term, limited duration plans and excepted benefits if the issuer receives federal financial assistance.

We also support the omission of Title IX's religious exemption, which is harmful and has no place in a health care nondiscrimination rule.

Definitions (§ 92.4)

We support the inclusion of a specific definitions section, bringing together many of the definitions relevant for effective implementation of § 1557.

We strongly support the 2022 Proposed Rule's recognition that providing health insurance and administering health coverage fall within the scope of "health programs or activities" subject to § 1557 protections.

We suggest closer alignment for the definitions related to qualified interpreter for a limited English proficient individual (LEP) and qualified interpreter for an individual with a disability. We believe all interpreters should demonstrate proficiency in speaking and understanding both English and a non-English language (including American or other sign languages), should interpret "without changes, omissions, or additions and while preserving the tone, sentiment, and emotional level of the original oral statement: and also adheres to generally accepted interpreter ethics principles including client confidentiality. These additions will provide alignment between the different types of interpreters and recognize that similar standards should apply whether an interpreter is interpreting for an LEP individual or a person with a disability.

Designation and responsibilities of a Section 1557 Coordinator (§ 92.7)

We appreciate the provision that covered entities must have a designated § 1557 coordinator. OCR requested comment on whether this provision should apply to entities with fewer than 15 employees and we recommend that the answer be yes. Even in smaller covered entities, it is essential that someone is responsible for coordinating implementation of § 1557 including developing the required policies and procedures, ensuring relevant employees are trained, receiving and addressing grievances, and informing individuals of their rights when they interact with the covered entity. There will not be a one-size-fits-all solution and a smaller entity would not have to have a full time coordinator. But we believe it is critical that all covered entities have a designated person to ensure compliance with the law and these regulations.

Individuals may choose to get care from smaller providers for a variety of reasons and these decisions should not impact their right to not face discrimination. For example, entities providing long-term services and supports (LTSS) to older adults and people with disabilities are often small in nature. These are often preferred by older adults and people with disabilities because the services they provide are often daily and intimate. Another example is that in many rural areas, some provider offices may have a small staff, yet people who live in low-density rural areas should not be at greater risk of facing discrimination. While preventing discrimination is critical in all health care settings, having a coordinator to ensure that 1557 is implemented is essential to daily life for someone who resides at a covered entity or receives home- and community-based services.

Policies and procedures (§ 92.8)

Requiring development of policies and procedures, and then requiring relevant staff to receive training, will hopefully ensure that covered entities are better able to meet the requirements of § 1557. We are unclear, however, whether the requirements to develop policies and procedures incorporate advance planning to identify what services might be required. We suggest that OCR either clarify this or specifically require covered entities to develop a communication access plan. For example, the 2022 Proposed Rule discusses the need for "language access procedures" which discusses how to schedule an interpreter, how to identify whether an individual is LEP, etc., but no requirement exists for a covered entity to think in advance of what types of language services it may need. That is, without gathering data about the populations in its service area and their communication needs, the entity may not be able to develop effective policies and procedures. This is also critical for entities where patients experience multiple intersecting communication barriers, such as individuals with limited English proficiency, have low literacy skills in their preferred language, and/or have an intellectual and/or physical disability. Further, covered entities should plan to ensure accessibility for individuals with physical and/or behavioral health disabilities. This should include compliance with the Medical Diagnostic Equipment Accessibility Standards that were finalized by the Access Board in 2016.

We recommend OCR modify § 92.8 to clarify that it must affirmatively develop a communication and accessibility plan before developing relevant policies and procedures. In the alternative, OCR could add a new provision requiring the development of a communication and accessibility plan prior to the development of policies and procedures. OCR should also develop and include a "model access plan", and explain how covered entities should develop one, in its Sec. 1557 rule, similar to the language access plan included in its 2013 LEP Guidance.

Entities that do not accurately know the population in its service area, or who do not know the full breadth of community resources that are available, risk not fully making health services accessible to all of its patients.

Training (§ 92.9)

We support the provision requiring training. We believe it is critical that not only individuals in "public contact" positions understand civil rights policies and procedures but also that those who make decisions about these policies and procedures understand the requirements of § 1557. Currently, the preamble to the 2022 Proposed Rule includes a definition of "relevant employees" but the regulatory language does not. We recommend including the definition either in this section or the Definitions section (§ 92.4).

Notice of nondiscrimination (§ 92.10)

We strongly support the requirements related to a notice of nondiscrimination. When this provision was removed in prior rulemaking, many individuals never received information about their rights; did not know how to access interpreters, auxiliary aids and services; and did not know how to file a complaint or a grievance.

In addition to the current requirements, we recommend OCR include in the notice requirement that any entity receiving a religious exemption under proposed section 92.302 include the existence and scope of such exemption in its required notices. It would be misleading and inaccurate to require entities to tell participants and beneficiaries and the public generally that the entity does not discriminate if the entity does in fact discriminate in certain circumstances and has been granted permission to do so.

Notice of availability of language assistance services and auxiliary aids and services (§ 92.11)

We strongly support this provision and the requirements for when this notice must be made available. We also recommend that if a covered entity operates across multiple states, that the covered entity has to provide the notice in not merely the top 15 languages in the aggregate (that is, adding to the top 15 languages across all the states) but rather the top 15 languages in each state. OCR should ensure that the top 15 languages by state are updated annually, as the language needs of a local population are subject to change from year to year as the nationalities of refugees, asylees, and immigrants with temporary protected status (TPS) change depending on immigration patterns, whether naturally or by necessity from geopolitical and climate crises. We also recommend that OCR require covered entities to require the notice include a large print statement, at least 18 point font, in addition to the top 15 languages. This will assist individuals with vision impairments to understand the importance of the notice. We also suggest that OCR develop and provide covered entities with model notices and translated information in the relevant languages that will be needed across the country. These notices should related to the different types of publications they are included on; that is, a notice would likely be different for a consent form versus information about a public health emergency versus a notice about one's rights or benefits.

SUBPART B – NONDISCRIMINATION PROVISIONS

Discrimination prohibited (§ 92.101)

We appreciate the specific section outlining the types of discrimination prohibited. We also strongly support the intersectional nature of § 1557 and urge OCR to identify other ways to address intersectional discrimination in the regulatory provisions of the 2022 Proposed Rule itself. As one example, we suggest that this provision (as well as others throughout the proposed rule) include a specific recognition of intersectional discrimination in the regulatory text itself.

While the Department acknowledges that discrimination based on "pregnancy or related conditions" includes protections against discrimination based on termination of pregnancy, the Department does not make that explicit in the regulatory text. Just as the Department should standardize its definition of "pregnancy or related conditions" throughout the regulatory text, it must also make clear that "termination of pregnancy" is specifically named in that definition. In the aftermath of the Supreme Court's *Dobbs* decision, individuals, especially people of color, people with low incomes, immigrants, young people,

people with disabilities, and LGBTQI+ individuals 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, such as transgender men who must navigate compounded stigma when seeking abortion care. In the wake of *Dobbs*, it is critical that abortion care is clearly and consistently included with "pregnancy or related conditions" throughout the final rule. Nationally, 20.9 million women have already lost almost all access to abortion care in their home states, and 58 percent—or 40 million—U.S. women of reproductive age live in states that are hostile to abortion rights. Nearly half of all abortion patients live below the federal poverty level.[9]

We also recommend that OCR add an explicit inclusion of transgender status. While the terms "gender identity" and "transgender status" are often used interchangeably, there have been instances in which those seeking to permit discrimination against transgender people have justified it by pressing distinctions between the two concepts. It is therefore preferable to enumerate both in the regulatory text.

SUBPART C – SPECIFIC APPLICATIONS TO HEALTH PROGRAMS AND ACTIVITIES

Effective communication for individuals with disabilities (§ 92.202)
and
Accessibility of information and communication technology for individuals with disabilities (§ 92.204)

We support the provisions on effective communication and accessible information and communication technology (ICT) requirements for people with disabilities. We also agree with the inclusion of mobile applications in § 92.204(b), which we believe will help spur greater awareness among software developers of the need for mobile applications that are fully accessible to people with disabilities and compatible with particular mobile devices and internet platforms that are favored for accessibility reasons.

In response to OCR's request for comments on whether the § 1557 rule should require covered entities to comply with specific online accessibility standards, we recommend requiring covered entities to comply over time with the latest WCAG guidelines as they are updated by the Web Accessibility Initiative.

We also recommend that § 92.202(b) explicitly parallel the language in § 92.201(b) by stating that auxiliary aids and services must be provided free of charge, be accurate and timely, and protect the privacy and the independent decision-making of the individual with a disability. While those requirements and others are incorporated through § 92.202(a)'s reference to 28 CFR 35.160 through 35.164, smaller covered entities that are creating 1557 policies and procedures without necessarily obtaining legal advice may simply look to §§ 92.201 and 92.202, noting the seeming difference in language between the subsections.

We are further concerned that proposed § 92.204 focuses on nondiscrimination and accessibility for individuals with disabilities only. Proposed § 92.204 should be applicable not just to individuals with disabilities, but to all individuals covered by § 1557.

Accessibility for buildings and facilities (§ 92.203)
and
Requirement to make reasonable modifications (§ 92.205)

We support these provisions which preserve prior existing requirements for structural accessibility and the provision of reasonable modifications. However, we strongly recommend incorporating existing standards relating to accessible medical and diagnostic equipment that were developed by the U.S. Access Board and finalized in 2017 within the proposed rule. For some people with disabilities, equipment accessibility is as necessary to equally effective healthcare as the accessibility of buildings and facilities, and is equally linked to requests for reasonable modifications in a covered entity's policies and procedures.

Equal program access on the basis of sex (§ 92.206)

We strongly support the inclusion of this section, which will help to address the myriad forms of harmful discrimination described above. Access to sexual and reproductive healthcare services is often barred by discriminatory policies but barriers to abortion care are especially pervasive. As a result of the *Dobbs* decision, many health programs and entities are struggling to understand their compliance with rapidly changing state laws. *Dobbs* also exacerbates long-standing pregnancy related discrimination for LGBTQ+, but especially transgender communities. In addition to the necessary examples of discrimination based on gender identity, it is important to include examples of reproductive health and pregnancy related care discrimination in § 92.206(b).

The provision also 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 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. We also recommend specific inclusion of transgender status in the regulatory text.

Nondiscrimination in health insurance coverage and other health-related coverage (§ 92.207)

Discriminatory Benefit Design

Despite protections in the ACA, insurers still seek to avoid high-cost populations such as people with

disabilities or chronic conditions, and others with high health needs. We support strong regulatory protections prohibiting discriminatory plan benefit design and marketing practices.

As just one example, private insurers often place unique annual coverage caps on durable medical equipment such as wheelchairs, commonly fail to provide any coverage for items such as hearing aids for adults, and place stringent utilization management controls on medications that are primarily used by people with specific chronic conditions such as AIDS/HIV. People with disabilities bear the bear the brunt of these kinds of benefit design decisions or omissions.

We also support the explicit requirement that health insurance coverage and health-related coverage must include the provision or administration of that coverage in the most integrated setting appropriate to the needs of covered individuals with disabilities. This provision acknowledges a fundamental tenet of disability rights law and the pivotal 1999 Supreme Court decision in *Olmstead v. Zimring*.

Gender Affirming and Transition-Related Care

We support the proposed rule's prohibition of nondiscrimination in the coverage of gender affirming and transition-related care. For years, studies have shown egregious disparities in accessing care for Transgender individuals. Transgender and Gender Diverse individuals commonly face insurance-related obstacles to obtain clinically appropriate care. These include 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 disparities only multiply 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 individuals from discriminatory benefit design and other practices by insurers which are contrary to well-established standards of care. We support the proposed rule, which realigns regulatory protections with the medical standards of care put forth by the World Professional Association of Transgender Health, American Medical Association, American Psychiatric Association, American Psychological Association, American Academy of Pediatrics, and other major medical associations.

Prohibition on sex discrimination related to marital, parental or family status (§ 92.208)

We recommend that the prohibition on discrimination of pregnancy or related conditions, including abortion, should not be listed in this provision. Including "pregnancy or related conditions, including abortion" discrimination could cause policies that are biased against single people experiencing 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 a person facing discrimination because they have had an abortion only occurs in a marital, parental, or family context. Entities writing policies will have clearer guidance by including discrimination based

on obtaining an abortion in the broader definition in § 92.101(a)(2) with examples listed in § 92.206(b).

Nondiscrimination on the basis of association (§ 92.209)

We support the restoration of explicit protections against discrimination on the basis of association. 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 relationship. As noted in the preamble, 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. It is important that the final rule make clear that this kind of associational discrimination is within the ambit of the rule's protections.

Nondiscrimination in the use of clinical algorithms in decision-making (§ 92.210)

We support the multiple examples cited in the preamble to the 2022 Proposed Rule of bias from clinical algorithms. The indiscriminate use of race-based clinical algorithms has no place in health care. Many clinical algorithms dictate that Black patients, in particular, 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.

That said, we point to the numerous examples of bias, discrimination, and harm by covered entities by the ADS that may fall outside the term "clinical algorithm." Such examples of harm include assessment tools for home and community-based services for both level of care determinations and services allocation that discriminate against groups or deny services needed to maintain community integration, eligibility systems for Medicaid, CHIP, or Marketplace coverage that wrongfully deny or terminate coverage, "gender conflicts" in health decisions that lead to misdiagnoses and discrimination in health care settings, utilization review practices that are based on financial motives rather than generally accepted standards of care and deny necessary behavioral health services, and service utilization control methods and payment rates that violate mental health parity.

We request that OCR broaden the 2022 Proposed Rule to include any form of automated decision making system because of the prevalence of automated decision making systems used by covered entities. At a minimum, HHS needs to define the term "clinical algorithms" because it may otherwise be too narrowly construed. For example, some may consider the Crisis Standard of Care Plans cited in the preamble as not "clinical algorithms" under a narrow definition because many were policies or ranking systems rather than automated decisions.

Nondiscrimination in the delivery of health programs and activities through telehealth services (§ 92.211)

We support the inclusion of the provision on telehealth and the recognition of it as a tool to improve access for patients who, for various reasons, are unable or prefer to receive services in person. Such need has been highlighted during the COVID-19 pandemic, when telehealth proved to be a life-saver for people across the country. While telehealth has been useful for all populations, telehealth has not been equitable for LEP patients and people with disabilities, and that service platforms are not yet made available at all to people with disabilities or people with limited English proficiency.

As a basic step, OCR should require telehealth platforms allow a third party interpreter or use of auxiliary aids and services. Second, all of the communication about telehealth that occurs prior to a telehealth appointment – *e.g.*, scheduling, system requirements, testing connections, telehealth appointment reminders, and log-on details – must be accessible to people with LEP and people with disabilities. Similarly, platforms should be adopted to meet the needs of people who are autistic, deaf or hard of hearing, blind, deaf/blind, movement impaired, or otherwise have difficulty in communicating via traditional telehealth models.

Some LEP patients who are immigrants might also have concerns regarding privacy in telehealth services and their immigration status. OCR should ensure that it is clearly communicated to patients that their information is secure, and not shared with law or immigration enforcement except under specific circumstances.[10]

SUBPART D – PROCEDURES

Enforcement mechanisms (§ 92.301)

We support strong enforcement of § 1557 and welcome OCR's recognition that the law protects people who experience intersectional discrimination. This can include individuals who experience both homophobia and racism, persons with disabilities who are pregnant or planning to become pregnant, older adults who are limited English proficient (LEP), and a transgender person may experience discrimination on the basis of sex (gender identity) and disability (diagnosis of gender dysphoria). We support clear, accessible procedures for filing, investigating, and remediating discrimination complaints. We also suggest OCR consider including a specific reference to intersectional discrimination in this provision.

Notification of views regarding application of Federal conscience and religious freedom laws (§ 92.302)

The federal government has a compelling interest in preventing discrimination in health care. The very purpose of § 1557 is to address long standing discrimination in health care that has created numerous barriers to quality care for communities of color, people with disabilities, the LGBTQ+ community, and more, but especially those who sit at the intersections of these identities. Religious exemptions have been used to discriminate against sexual and reproductive health care, LGBTQ+ competent care, and actively

exacerbate health disparities. Rural communities, people with low-incomes, and communities of color often rely on religiously affiliated health care entities which make up a large part of the U.S. health care system. In fact, women of color disproportionately give birth in Catholic hospitals and are therefore refused many facets of comprehensive sexual and reproductive health care.

Under the Religious Freedom Restoration Act (RFRA), if a regulation places a substantial burden on religious exercise the government must prove they have a compelling interest and are using the least restrictive means possible. In the context of discrimination in health care, the government has the strongest compelling interest to not only prevent discrimination but ensure taxpayer dollars are not used to further discrimination. By participating in a federal health program and receiving federal funding recipients must be held to the highest anti-discrimination standard so people can access the sexual and reproductive health care they need and deserve.

To adhere to §1557's goals and ensure patient well-being is paramount, OCR's review process for exemptions must address this compelling interest in each case-by-case analysis. Determinations must clearly explain how any exemption granted does not further discrimination and any exemption denied would have undermined the goals of § 1557. Additionally, determinations of discrimination cannot be unduly delayed as people harmed by health care discrimination are often dealing with increased negative health outcomes or have been forced to forgo care entirely.

OTHER PROVISIONS

Regulatory Provisions affecting other programs (Medicaid, CHIP, PACE, etc.)

We support the provisions reinstating prohibitions of discrimination based on sexual orientation and gender identity in Medicaid and the Children's Health Insurance Program (CHIP), including managed care entities and their contracts, as well as Programs for All-Inclusive Care for the Elderly (PACE). We urge HHS to harmonize the regulatory protections in these programs with the inclusive language proposed in the § 1557 provisions to specify that sex includes, but is not limited to, discrimination on the basis of sex stereotypes; sex characteristics, including intersex traits; pregnancy or related conditions; sexual orientation; and gender identity. Harmonizing regulatory language across programs will allow greater clarity for compliance and enforcement.

For people with Medicaid, hospitals have been reported to provide the bare minimum in care; including the quality of care, long wait times (e.g. up to 5 hours for care), and disrespecting/patronizing patients. In addition to inherent bias among health professionals leading to discrimination, this could be due to historically low reimbursements for Medicaid payments.[11] Additionally, patient satisfaction ratings in hospitals are rarely sought after.[12]

There is also the grave concern of Medicaid patients being used for facilities to receive more payments. For example, with the young people CLASP works with, one person reported having had multiple of the

same doses of the same vaccine, or having additional diagnostic tests and procedures done for medical concerns that seemed to go away without explanation. With enforcement of anti-discrimination measures, particularly for people who access Medicaid, these types of Medicaid fraud issues would be identified and ideally rectified.

OTHER ISSUES

Demographic Data Collection

The 2022 Proposed Rule acknowledges that demographic data collection and civil rights enforcement are inextricably linked. For example, racial and ethnic minority women receive poorer quality care than racial and ethnic minority men, who receive poorer care than white men. Spanish-speaking Hispanics experience poorer quality care than English-speaking Hispanics, who experience poorer care than non-Hispanic whites. Compared to women without disabilities, women with disabilities are more likely not to have regular mammograms or Pap tests. Racial and ethnic minorities with disabilities experience greater disparities in diagnoses and utilization of assistive technology.

OCR should adopt a demographic data collection requirement and establish demographic data collection as a function of civil rights monitoring. Demographic data collection requirements should align with the demographic characteristics enumerated within the rule: race, ethnicity, language, disability, age, sex, sexual orientation, gender identity, pregnancy status, and sex characteristics. HHS has already established or acknowledged recommended practices for engaging in demographic data collection in each of these demographic categories. HHS should adopt those existing data collection practices and engage in additional research where necessary. With any demographic data collection requirement, HHS must be sure to provide appropriate training and technical assistance resources to programs and grantees. Collecting accurate data, including race, ethnicity, and primary language, is critical to provide essential and effective health services.

Arab Americans are overlooked and ignored in health research throughout the United States. Due to the absence of a MENA (Middle Eastern/North African) race category, there is a lack of accurate data for this ethnic group. Failing to include them or incorrectly categorizing them, exacerbates health inequities, glossing over health concerns and issues. Not seeing trends in Arab American communities, due to the social determinants of health, can create a blind spot in preventive health care measures, causing adverse health conditions when issues are found too late. For instance, language barriers and cultural responsiveness of providers impact the quality of mental health care. Without proper data collection disaggregated by race/ethnicity and geography, it is difficult to determine what services in a locality should be provided in specific languages. This becomes incredibly important with the health professional-patient relationship, and particularly with mental health care, which is already very stigmatized. Cultural and social barriers impact the quality of mental healthcare these populations receive.

Additionally, by considering Middle Eastern and North African groups as the same population,

researchers and health professionals are doing both populations a disservice. In current U.S. Census data, Arab Americans/MENA individuals are erroneously classified as Caucasians, masking differences between populations. Without accurate data, health professionals cannot gauge the support and type of resources needed for these communities.

To advance racial and ethnic health equity, we must include a MENA race category across data platforms, disaggregate the category when possible, and respect the diverse etiology of various ethnic groups so we may better understand their health risks and outcomes and which public health interventions may be needed. Disaggregating by race and ethnicity is essential; data must also not collect Asian American, Native Hawaiian, and Pacific Islander communities as an aggregate. Once accurate data is collected, effective public health interventions can be proposed and studied to provide culturally responsive mental health care for these ethnic populations.

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 protections will help to ensure that data collected can be best utilized to prevent discrimination and disparities in health care and access.

Discrimination based on Race and Ethnicity

While the proposed rule does not have specific provisions related to discrimination based on race and color, we do want to emphasize the importance of protecting individuals from this discrimination and the compounding impact race and color can have on intersectional discrimination. Discriminatory health care systems and policies play an outsized role in the ability of people of color to access quality health care in the United States. Given the deep legacy of racism and other forms of discrimination in health systems and health policy, § 1557 of the Affordable Care Act is a significant step towards rectifying centuries of policies and practices that have created worse health outcomes for underserved groups.

This 2022 Proposed Rule not only clarifies the broad civil rights protections extended in § 1557, but provides concrete tools to combat racism and other forms of discrimination in health care. First, the 2022 Proposed Rule addresses various forms of discrimination that disproportionately affect communities of color, including on the basis of disability status, age, national origin, and sex. Second, the 2022 Proposed Rule addresses systemic discrimination, including policies and practices that harm people of color. Ultimately, we support this Proposed Rule as an important regulatory effort to address discrimination and racism in health care.

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 anti-discrimination protections to patients at the intersection of multiple identities. The 2022 Proposed Rule proscribes many forms of discrimination that amplify the impacts of racism and subject people to dual discrimination. For example, the 2022 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. 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.

It has been long recognized that the denial of adequate language services to LEP individuals constitutes discrimination on the basis of national origin. However, there are clear intersections between LEP status and race and/or ethnicity. According to the most recent data, 63% of LEP individuals are Latinx and 21% are Asian/Pacific Islander. Moreover, according to one study, a "substantial number of Asian Americans reported encountering racial discrimination and possessing limited English proficiency." Another study revealed that "more than half (65%) of [patients in the study] indicated that they have felt discriminated against by [health care] staff because of their Hispanic ethnicity or LEP." Improving language access services is therefore a critical tool to addressing discrimination against people of color by health care providers.

Improving health care access for people living with disabilities is critical to reducing racial health disparities. Black people are more likely to have a disability relative to White people in every age group, and according to the National Disability Institute, 14% of Black people live with disabilities compared to 11% of Non-Hispanic Whites and 8% of Latinos.

The 2022 Proposed Rule clarifies discrimination on the basis of sex as including, but not limited to, discrimination on the basis of sex stereotypes; sex characteristics, including intersex traits; pregnancy or related conditions; sexual orientation; and gender identity. Proscribing discrimination on these bases will improve health care access for LGBTQI+ people of color, in particular. Further, 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 experience denial of care and medical abuse than white transgender people. That report further notes that transphobia is often inseparable from racism and sexism in the medical system. 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. Furthermore, some transgender people report experiencing such hostile discrimination that doctors have refused to treat conditions such as asthma or diabetes.
OCR properly notes that racial health disparities in the United States are directly attributable to "persistent bias and racism" in the health care system. Both intentional and unintentional race discrimination serve as barriers to care, lead to lower quality care, and drive worse health outcomes for communities of color. Discrimination in health care is often systemic—deeply embedded within the policies, procedures, and practices of covered entities.

CONCLUSION

We have included numerous citations to supporting research, including direct links to the research. We direct OCR to each of the materials we have cited and made available through active links, and we request that the full text of each of the studies and articles cited, along with the full text of our comment, be considered part of the formal administrative record for purposes of the Administrative Procedure Act. If OCR is not planning to consider these materials part of the record as we have requested here, we ask that you notify us and provide us an opportunity to submit copies of the studies and articles into the record.

Thank you for the opportunity to comment on this important issue. If you have further questions, please contact Isha Weerasinghe, Senior Policy Analyst, at iweerasinghe@clasp.org.

Sincerely,
CLASP

---

[1] https://www.healthaffairs.org/doi/10.1377/hlthaff.2021.01466
[2] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4843483/
[3] https://www.law.cornell.edu/wex/redlining
[4] https://www.povertyactionlab.org/evaluation/discrimination-job-market-united-states
[5] https://www.brookings.edu/essay/homeownership-racial-segregation-and-policies-for-racial-wealth-equity/
[6] https://www.census.gov/library/stories/2020/09/poverty-rates-for-blacks-and-hispanics-reached-historic-lows-in-2019.html#:~:text=In%202019%2C%20the%20share%20of,23.8%25%20of%20the%20poverty%20population
[7] https://www.kff.org/medicaid/issue-brief/medicaid-and-racial-health-equity/
[8] https://www.bu.edu/antiracism-center/files/2022/06/Anti-Black.pdf
[9] https://www.guttmacher.org/united-states/abortion/demographics
[10] https://www.ajmc.com/view/addressing-virtual-care-disparities-for-patients-with-limited-english-proficiency
[11] https://www.healthaffairs.org/doi/10.1377/hlthaff.2021.01466
[12] https://www.npr.org/sections/health-shots/2022/09/08/1121647094/patient-satisfaction-surveys-fail-to-track-how-well-hospitals-treat-people-of-co