FLORIDA HEALTH JUSTICE PROJECT

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

October 3, 2022

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

Dear Director Fontes Rainer:

Florida Health Justice Project 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")

Florida Health Justice Project (FHJP) is a statewide organization committed to expanding access to healthcare for Florida's most vulnerable and marginalized residents, and to improving health equity.

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 and Medicare, the ACA's state and federal Marketplaces and the plans sold through them, as well as other commercial health plans if the insurer receives any form of 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. Religious exemptions are ultimately a veil for discriminatory practice. The danger of discrimination is present at the level of the individual provider, the institutional health program or system, or the payer. At any level, discriminatory practices that result in the exclusion of e.g. abortion services, or HIV treatment deserve no protection under law.

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. 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.

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.

Additionally, covered entities need to have active obligations to notify members and beneficiaries of their right to request effective communication and auxiliary aids and services, including recording granular information about disability function and accommodation needs in electronic health records. People with disabilities over 18 years have significantly less access to cellular/broadband internet access than those without disabilities. Household residents with disabilities 45 years and over have 9-10% less access than their similarly aged non-disabled peers.

SUBPART B – NONDISCRIMINATION PROVISIONS

Discrimination prohibited (§ 92.101)

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.

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.

In a state where both abortion access and gender-affirming care are under attack, we underscore the importance of these points.

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.

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.

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 brunt of these kinds of benefit design decisions or omissions.

A further example: in Florida we routinely see provider networks that lack sufficient access, or that place undue burdens on access, to key specialists for e.g. treatment for various disabilities, or to culturally competent providers.

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.

We have seen in recent months in Florida the escalating attacks on transgender residents, and the state has already issued a rule denying Medicaid coverage of gender-affirming care. We, together with legal partners, have brought suit against the state for this illegal action. It is critical that federal protections make explicit that coverage exclusions of gender-affirming services is a violation of federal law. Without clarity in the federal rule, residents of states across the country will be facing these illegal limits on coverage.

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.

In Florida, where members of the LGBTQ community are under attack, and the passage of the "Don't Say Gay or Trans" bill revealed the fearful backlash to normalizing LGBTQ identities, discrimination based on association is all too real a possibility to ignore.

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, given 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.

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.

As noted above, Florida is one of numerous states using transgender children as a pawn in today's culture wars. To protect against their discrimination in healthcare, and that of their senior counterparts, protections must extend across all health coverage programs and contract entities.

OTHER ISSUES

Demographic Data Collection

The 2022 Proposed Rule acknowledges that demographic data collection and civil rights enforcement are inextricably linked. We cannot act on health disparities unless we know about them.

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.

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.

We have seen in Florida how a lack of data impacts the ability to fully understand the scope and scale, and the subtleties of disparities. Only with a clear understanding, can appropriate and effective interventions and remediation be undertaken.

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 historically marginalized and underserved groups. In the Southern states that have not expanded Medicaid, we witness this legacy daily.

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. In a city like Miami, where nearly 55% of the residents are immigrants, these protections are essential.

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.

Accessible Medical and Diagnostic Equipment

We appreciate OCR's invitation to comment on the importance of adopting the Access Board's 2017 Medical Diagnostic Equipment Accessibility Standards into enforceable regulation. We now have had almost six years to see what individual health providers and facilities, health care systems, hospitals, health insurers, and federal and state health care agencies would voluntarily do with the detailed, thorough consensus standards developed by the Access Board, and the answer is "very little." The U.S. Department of Veterans' Affairs adopted the standards soon after their completion and

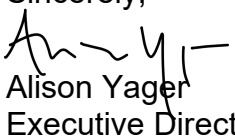
applies them to the agency's new equipment acquisitions but this example was not followed by others. In those five years, people with mobility, developmental, and strength and balance disabilities across a range of ages, different races/ethnicity, and LGBTQ+ status have continued to be denied access to the most basic medical procedures: a physical exam and an accurate measure of weight.

Inaccessible equipment is not a matter of mere inconvenience. Even if a disabled person has a family member or friend who might be able to accompany them to an appointment and provide transfer assistance, the consequences of doing so are borne unequally by low-income individuals and families of color who are least able to afford time off. The ability to receive effective healthcare in one's own community, with one's freely chosen provider, in a manner that is as timely and appropriate as the care received by persons without disabilities, should not depend on whether one uses a wheelchair or has certain chronic conditions or is aging, but without enforceable medical diagnostic equipment standards this is the reality for thousands of people with disabilities.

CONCLUSION

Thank you for the opportunity to comment on this important issue. If you have further questions, please contact Alison Yager at yager@floridahealthjustice.org.

Sincerely,



Alison Yager
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