

Questions and Answers on the 2024 Final Rule Addressing Nondiscrimination Protections under the ACA's Section 1557

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In courts and through regulatory action, the Biden-Harris administration has been vigorously working to promote health equity. This includes strengthening its implementation of § 1557, the Affordable Care Act's (ACA) nondiscrimination provision. On May 6, 2024, the Department of Health and Human Services' (HHS) Office for Civil Rights (OCR) published a final rule that would reinstate key regulatory text on the ACA's nondiscrimination requirements repealed by the prior administration. The final rule also includes new provisions responding to recent legal and policy developments.

This issue brief provides background on § 1557, the Biden administration's 2024 Final Rule (2024 Final Rule), and what you can do to support the implementation and enforcement of these important legal protections. For the purposes of this issue brief, we refer to four different § 1557 proposed or final rules:

- 2016 Final Rule¹ (issued by the Obama Administration);
- 2020 Final Rule² (issued by the Trump Administration);
- 2022 Proposed Rule³ (issued by the Biden Administration); and
- 2024 Final Rule⁴ (issued by the Biden Administration).

This issue brief is divided into four sections:

- <u>Background</u> (Questions 1–6)
- 2024 Final Rule Specific Application to Protected Groups (Questions 7–15)
- <u>2024 Final Rule Other Provisions and Effective Dates</u> (Questions 16–19)
- How to Get Involved or File a Complaint (Questions 20–21)

Background

This section includes the following questions and answers:

- Q.1 What is § 1557?
- Q.2 Does § 1557 address intersectional discrimination?
- Q.3 What kinds of programs and providers must comply with § 1557?
- Q.4 What is the scope of the 2024 Final Rule?
- Q.5 Why did the Biden administration revise the 2020 Final Rule?
- Q.6 Does the 2024 Final Rule expand the applicability of § 1557?

Q.1 What is § 1557?

A. Section 1557 is the nondiscrimination provision of the ACA.⁵ It prohibits discrimination in: health programs and activities receiving federal financial assistance; health programs and activities administered by the executive branch; and entities created under the ACA, including the Marketplaces and health plans sold through the Marketplaces. Section 1557's protections extend to discrimination on the basis of race, color, national origin (including limited English proficiency and primary language), sex (including pregnancy or related conditions; sexual orientation; gender identity; sex stereotypes; and sex characteristics, including intersex traits), age, disability, or any combination thereof by incorporating and expanding upon components of pre-existing federal civil rights laws.⁶ It is the first federal law to ban sex discrimination in health care.

Section 1557 went into effect the day the ACA became law on March 23, 2010. The provision is self-implementing, meaning it does not rely on rules to take effect. HHS underwent an extensive process to develop its initial rules on § 1557, including a Request for Information, proposed rule, and the 2016 Final Rule.⁷ The Trump Administration then proposed changes to 2016 Final Rule which were finalized in its 2020 Final Rule.⁸ Now, after proposing changes via its 2022 Proposed Rule, the Biden-Harris administration is finalizing changes to the 2020 Final Rule through the 2024 Final Rule.

Q.2 Does § 1557 address intersectional discrimination?

A. Section 1557 is intended to protect individuals from discrimination in health care on the basis of all the protected categories—race, color, national origin, sex, age, and disability. Additionally, § 1557 recognizes that people often experience discrimination based on more than one protected category, a fact unaddressed by previous civil rights laws, which each focused on only selected groups (*e.g.*, Title VI protected individuals from discrimination on

the basis of race, color and national origin while Section 504 protected individuals from discrimination on the basis of disability). Prior to § 1557, the challenge for individuals facing multiple forms of discrimination was that each civil rights law has unique requirements and sometimes differing legal standards to prove discrimination. For example, if an Latina woman with a disability experienced discrimination when seeking health care, it may be impossible to separate out only one of her identities (*i.e.*, race, disability, and sex) as the basis of discrimination, but she might have had to file separate complaints or meet different standards to prove discrimination on each identity and prior to enactment of § 1557 sex discrimination was not prohibited. Under § 1557, she has the same rights for her intersecting identities.

The majority of federal courts have correctly recognized that discrimination on the basis of a combination or the interrelationship of multiple protected characteristics is actionable under federal nondiscrimination laws. These courts recognize that "where two bases of discrimination exist, the two grounds cannot be neatly reduced to distinct components" because they often "do not exist in isolation." For example, "African American women are subjected to unique stereotypes that neither African American men nor white women must endure." The 2024 Final Rule also explicitly recognizes intersectional discrimination by adding language saying an individual may not face discrimination "on the basis of race, color, national origin, sex, age, disability, **or any combination thereof**" (emphasis added). 11

Q.3 What kinds of programs and providers must comply with § 1557?

A. Section 1557 applies to health care programs and activities receiving federal financial assistance or funding; programs run by the federal government, including Medicare and the federal marketplace (healthcare.gov); and entities created under Title I of the ACA. While § 1557 applies across the entire federal government, the 2024 Final Rule only addresses health programs and activities within HHS.

Entities subject to § 1557 ("covered entities") include virtually all health care providers (*e.g.*, hospitals, clinics, health care provider's offices, and pharmacies) and issuers selling health insurance plans within and outside of the ACA Marketplaces, so long as they receive federal financial assistance. ¹² If an entity is principally engaged in providing or administering health services or health insurance coverage, the 2024 Final Rule states that all of its activities are covered by § 1557 if any part receives federal financial assistance. ¹³

The 2024 Final Rule restores provisions that recognize § 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.¹⁴ The Final Rule further clarifies that § 1557 applies to <u>short term, limited duration plans</u> and excepted benefits if the issuer receives federal financial assistance.¹⁵ These plans are exempt from ACA coverage requirements such as <u>Essential Health Benefits</u>, but are subject to § 1557.

Under the law (and underscored in the 2016 Final Rule and 2024 Final Rule), when an entity is principally engaged in providing or administering health services, all of its activities are covered by § 1557 if any part receives federal financial assistance. This means, for example, that if a hospital system receives federal funding to transition to electronic medical records, then the entire hospital operations, including outpatient clinics, surgical units, and labs, must comply with § 1557. The 2020 Final Rule sought to exempt most health insurance plans and federal health programs from § 1557, despite the law's plain language that states it applies to "any health program or activity, any part of which receives federal financial assistance," as well as health programs "administered by an executive agency." ¹¹⁶

Q.4 What is the scope of the 2024 Final Rule?

A. Section 1557 is critical both in the scope of discrimination prohibited as well as its recognition of intersectional discrimination.

In the 2024 Final Rule, the administration seeks to:

- apply nondiscrimination protections to a broad array of health care programs and entities;
- require notices that inform individuals of their rights and require training of staff
 who interact with the public and those who determine the entity's § 1557 policies
 and procedures;
- ensure protection against sex discrimination, which includes sex characteristics, including intersex traits; pregnancy or related conditions; sexual orientation; gender identity and sex stereotypes. This covers discrimination for women and LGBTQI+ people, including but not limited to discrimination related to sexual, reproductive, and gender-affirming care;
- ensure that persons with limited English proficiency (LEP) and people with disabilities can access health care services with the communication or other assistance they may need to do so;

- reinstate protections against discriminatory health plan benefit design and prohibit discrimination in telehealth, "patient care decision support tools," and on the basis of association; and
- prohibit discrimination by religiously affiliated hospitals, providers, and health plans
 while recognizing individual providers who have a religious or conscience objection
 can, in limited circumstances, be exempt from providing certain health care services.

The 2024 Final Rule also changes HHS policy, affirming for the first time that § 1557 applies to Medicare Part B, determining that payments made under Part B do constitute "federal financial assistance". When Medicare was first enacted in 1965, the federal government made payments directly to Medicare Part A providers (e.g., hospitals) but did not directly pay Medicare Part B providers (e.g., outpatient providers), instead sending payments to enrollees who then paid the Part B providers. Thus, HHS concluded that Part B providers did not receive federal financial assistance because the payments went to the enrollee and often did not cover the full amount billed by the provider. HHS also excluded these payments by defining them as "contracts of insurance" which were exempt from prior civil rights statutes. Despite the specific inclusion of "contracts of insurance" in the § 1557's statutory text and changes in the operation of Medicare whereby the federal government now directly pays Part B providers, HHS did not initially apply § 1557 to Part B providers. The 2024 Final Rule recognizes that both the statutory text of § 1557 as well as the change in how Medicare Part B providers are paid results in § 1557's application to Medicare Part B providers. It further applies prior civil rights statutes to Medicare Part B as well—Title VI and IX of the Civil Rights Act, Section 504 of the Rehabilitation Act, and the Age Act. 17

This clarification is important for people with disabilities, as Medicare Part B provides essential coverage, including preventive care, durable medical equipment, mental health and substance disorder treatment, to many individuals under age 65 with disabilities, as well as older adults with disabilities. It also is important for individuals with limited English proficiency to ensure language access services are available for services provided solely through Medicare Part B.

Q.5 Why did the Biden administration revise the 2020 Final Rule?

A. The administration cites a number of reasons for revising the 2020 Final Rule. The 2022 Proposed Rule says the rulemaking will better align the rules with the statutory text of § 1557. The changes reflect recent developments in civil rights law, address unnecessary confusion in compliance and enforcement that arose from the 2020 Final Rule, and better

address issues of discrimination. The administration also considered civil rights issues raised during the coronavirus pandemic.¹⁸

First, after the 2020 Final Rule was finalized, the Supreme Court decided that sex discrimination includes discrimination on the basis of sexual orientation and gender identity.¹⁹ On May 10, 2021, HHS publicly announced, consistent with this decision, that it would interpret § 1557's prohibition on sex to include sexual orientation and gender identity (*see* Q&A 8).²⁰

Second, the administration concluded that the 2020 Final Rule caused unnecessary confusion in compliance with § 1557 by not providing clear procedural requirements. Further, the 2020 Final Rule "significantly" pared down regulatory language related to the specific discriminatory activities prohibited. HHS has since recognized that covered entities and protected individuals need additional clarity regarding the specific discriminatory actions prohibited. Unfortunately, many individuals may face discrimination based on intersectional factors (*e.g.*, an Asian American transgender man may face both race and sex discrimination) and the 2020 Final Rule did not address this.

Third, this administration has demonstrated a significant commitment to promoting health equity through a series of Executive Orders as well as health care and health-related policies at HHS and other agencies. Prior to the issuance of the proposed rule, President Biden issued more than 12 directives aimed at promoting equity, including civil rights enforcement.²¹ The 2024 Final Rule furthers the administration's commitments in these areas. The preamble to the 2022 Proposed Rule includes a significant discussion of the importance of health equity and the ongoing discrimination many individuals continue to face based on race, color, national origin, sex, sexual orientation, gender identity, sex stereotypes, sex characteristics, age, disability, or any combination thereof.²²

Q.6 Does the 2024 Final Rule expand the applicability of § 1557?

A. No. Agencies such as HHS **cannot** expand the applicability of federal laws, including § 1557. Thus, the 2024 Final Rule helps clarify who is protected under the law and which entities are subject to its requirements, but does not expand its protections or application beyond the statutory parameters.

2024 Final Rule – Specific Applications to Protected Groups

This section includes the following questions and answers:

- Q.7 How does the 2024 Final Rule address discrimination on the basis of sex?
- Q.8 How does the 2024 Final Rule affect LGBTQI+ persons?
- Q.9 How does the 2024 Final Rule address pregnancy or related conditions?
- Q.10 How does the 2024 Final Rule address sex stereotypes in health care?
- Q.11 How does the 2024 Final Rule impact people with HIV/AIDS and other serious or chronic medical conditions?
- Q.12 How does the 2024 Final Rule address health care refusals based on religious or moral beliefs?
- Q.13 How does the 2024 Final Rule affect individuals with limited English proficiency (LEP)?
- Q.14 How does the 2024 Final Rule affect people with disabilities?

Q.7 How does the 2024 Final Rule address discrimination on the basis of sex?

A. Discrimination on the basis of sex and intersecting identities, such as race, color, national origin, disability, and age, is pervasive in our health care system. This discrimination undermines the health of women and Lesbian, Gay, Bisexual, Transgender, Queer and Intersex plus (LGBTQI+) people in a myriad of ways. Section 1557 of the ACA was the first federal law to prohibit sex discrimination in health care.²³ HHS's new final rule reaffirms and clarifies the law's related protections in a number of ways.

First, the 2024 Final Rule reinstates a regulatory definition of discrimination on the basis of sex, which HHS initially included in its 2016 Final Rule and then removed in 2020.²⁴ HHS's new definition of sex discrimination in § 92.101 "includes, but is not limited to, discrimination on the basis of sex characteristics, including intersex traits; pregnancy or related conditions; sexual orientation; gender identity; and sex stereotypes."²⁵ For the first time, this definition explicitly includes sexual orientation and sex characteristics (including intersex traits), which HHS previously declined to explicitly enumerate in its 2016 sex discrimination definition.²⁶ To further clarify forms of prohibited sex discrimination, the Final Rule restores and revises a section on equal program access on the basis of sex (§ 92.206) and promulgates a new section on sex discrimination related to marital, parental, or family status (§ 92.208).²⁷

Together, HHS's amendments to § 1557 regulations and preamble to the Final Rule show promise for countering and reducing sex discrimination in access to health insurance

coverage, care delivery, and other covered health programs and activities for LGBTQI+ people and women. We explore related issues in Questions and Answers 9–12.

Q.8 How does the 2024 Final Rule affect LGBTQI+ persons?

A. The 2024 Final Rule reinstates regulatory protections against discrimination for LGBTQI+ individuals that were removed in the 2020 Final Rule and expands on the protections that were enumerated in the 2016 Final Rule. The 2024 Final Rule clarifies that discrimination on the basis of sex includes discrimination based on sex stereotypes, sexual orientation, gender identity, and sex characteristics including intersex traits.²⁸

The preamble to the 2024 Final Rule notes "[i]t is well documented that LGBTQI+ people face significant health disparities and barriers to health care and insurance coverage."²⁹ The 2024 Final Rule recognizes that, especially in light of the Supreme Court's 2020decision in *Bostock*, § 1557's prohibition of discrimination on the basis of sex in health care programs and activities must extend to protect people against discrimination on the basis of sexual orientation and gender identity.³⁰

The 2024 Final Rule explicitly prohibits sex discrimination for the purposes of § 1557 to include "discrimination on the basis of sex stereotypes; sex characteristics, including intersex traits; . . . sexual orientation; and gender identity."³¹ This provision is designed to provide protection from discrimination based on sex stereotypes, which are assumptions about how an individual should look, act, or present themselves that are based on their sex. Thus, for example, if a health clinic refused to provide care to a cisgender, heterosexual woman with a buzz cut because her gender presentation was not stereotypically feminine, that could constitute sex discrimination (*see* Q&A 10 for further discussion on sex stereotypes).

Similarly, the 2024 Final Rule clarifies that § 1557 prohibits discrimination against LGBTQ people based on their sexual orientation.³² Thus, for example, a hospital's policy to only place Gay men in single rooms, when it places heterosexual men in shared rooms, could constitute sex discrimination.

The 2024 Final Rule also protects Transgender, Non-Binary, Gender Non-Conforming, and other individuals from discrimination based on gender identity.³³ Thus, for example, if a pharmacist asked a Non-Binary person questions about their genitals before administering a vaccination, when the pharmacist did not ask those questions of cisgender people, that could constitute discrimination.

Finally, the 2024 Final Rule protects Intersex, Transgender, Non-Binary, Gender Non-Conforming, and other individuals based on variations in sex characteristics—genitals, gonads, chromosomes, hormonal factors, or other physical sex characteristics.³⁴ These protections are especially important for Intersex people who have sex characteristics that do not fit typical binary definitions of male or female bodies. Thus, for example, if a clinician refused to prescribe medically necessary hormone therapy to an Intersex person, but prescribes hormone therapy to non-Intersex patients, that refusal could constitute discrimination. The 2024 Final Rule also protects Transgender, Non-Binary, and other people from discrimination based on variations in and/or perceived sex characteristics that do not fit typical binary definitions of male or female bodies. For example, if a clinician refused to provide a prostate exam to a Transgender woman because she has breasts and a vulva, that could be discriminatory.

The 2024 Final Rule also has several other provisions specifically aimed at protecting LGBTQI+ people, especially TQI+ (Transgender, Queer and Intersex) people. It explicitly requires equal access to health programs and activities without discrimination based on sex.³⁵ These provisions provide specific protections for Intersex, Transgender, Non-Binary, Gender Non-Conforming, and other individuals to access medically necessary care by implementing specific protections to ensure access to necessary gender-affirming and transition-related care, and protections to ensure access to so-called "sex specific" care (such as mammograms and prostate exams) regardless of someone's sex assigned at birth, recorded gender, or gender identity.³⁶ The 2024 Final Rule also explicitly prohibits categorical coverage exclusions of transition-related and gender-affirming services.³⁷

In addition, the rule prohibits sex discrimination based on "marital, parental, or family status." This provision provides explicit protections for LGBTQI+ people in non-traditional familial and romantic relationships. For example, a hospital refusing to allow a pregnant woman's female partner to accompany them to prenatal visits, while allowing the male partners of other pregnant women to attend prenatal visits, could constitute sex discrimination.

Q.9 How does the 2024 Final Rule address pregnancy or related conditions?

A. HHS clarifies § 1557's protections against discrimination related to pregnancy or related conditions in a number of ways throughout the 2024 Final Rule. First, HHS reaffirms these protections by explicitly including discrimination related to pregnancy or related conditions in its regulatory definition of sex discrimination.³⁹ In the preamble, HHS recognizes that discrimination related to pregnancy or related conditions can "negatively affect an individual's ability to make decisions about their reproductive health and life, and their

ability to be equal and participating members of society."⁴⁰ HHS clarifies § 1557's protections against related discrimination as follows:

Abortion. As background, the 2016 Final Rule on § 1557 defined sex discrimination to include "discrimination on the basis of pregnancy, false pregnancy, termination of pregnancy [*i.e.*, abortion], or recovery therefrom, childbirth or related medical conditions, sex stereotyping, and gender identity."⁴¹ Later that year, a federal district court barred HHS from implementing the regulations' prohibition against discrimination on the basis of gender identity or abortion.⁴² In 2020, the Trump Administration removed HHS's definition of sex discrimination from § 1557 regulations.⁴³ In 2021, the court prevented HHS from enforcing § 1557's gender identity and abortion protections against the plaintiffs in the case, a group of religiously affiliated health plans and several states.⁴⁴

While HHS did not explicitly include "termination of pregnancy" in the 2024 Final Rule's regulatory definition of sex discrimination, in the preamble, it reaffirmed that § 1557's protections against discrimination related to pregnancy or related conditions includes abortion. HHS offered examples of abortion-related discrimination that may violate § 1557. For example, covered entities may not discriminate against people for their pregnancy-related decisions, past, present, or future. A covered provider may violate § 1557 if they generally provide abortions but refuse to do so for to a particular individual based on their race or disability. Further, if a treating physician prescribes antibiotics to address a miscarriage-related uterine infection and a pharmacy refuses to fill that antibiotic due to concerns that subsequent care may include an abortion, they may be engaging in prohibited sex discrimination under § 1557. However, HHS stressed that the Final Rule does not require the provision of any specific services. Overed entities may be exempt from these protections under federal health care refusal laws (e.g., based on religious objections) and may also refuse to provide abortions when based in a nondiscriminatory professional or business judgement about the scope of services they wish to offer).

Maternal health. Due to systemic sexism and intersecting racism, ableism, and other forms of discrimination, mistreatment in health care delivery during labor and delivery and the prenatal and postpartum periods is widespread. In 2019 a national survey of over 2,700 women, one in six reported mistreatment during childbirth.⁵¹ Rates were highest for Indigenous (32.8%), Hispanic (25%), and Black women (22.5%). Further, a 2018 California survey found that Black, Asian, and Pacific Islander women who gave birth in hospitals reported higher rates of mistreatment such as harsh language and rough handling during their stays than white women.⁵² In the preamble to the Final Rule, HHS affirms that depending on the specific facts at issue, if a covered entity subjects a person who is pregnant, in labor, or postpartum to rough handling, harsh language, undertreatment of

pain or pregnancy-related conditions, or other discriminatory mistreatment, they may violate § 1557.⁵³

Assisted reproduction. In the preamble, HHS clarifies that if a covered entity opts to provide or cover assisted reproduction services such as fertility services but denies them to same-sex couples, it may violate § 1557.⁵⁴

Pregnancy-related discrimination against people with chronic health conditions.

Since the Supreme Court overturned the constitutional right to abortion in *Dobbs v. Jackson Women's Health Organization*, people who are not pregnant have faced a surge in barriers to medications prescribed to treat chronic health conditions on the basis that the drugs have properties that can terminate or cause complications to hypothetical pregnancies.⁵⁵ For example, some health care providers have refused to prescribe or call in refills for prescriptions to treat symptoms of conditions such as rheumatoid arthritis and Ehlers-Danlos syndrome.⁵⁶ Some health insurers are refusing to cover these medications.⁵⁷ Further, some retail pharmacies are denying or delaying refills for these medications.⁵⁸ In the preamble to the 2024 Final Rule, HHS reaffirms that if a covered entity denies a person access to a medication prescribed for their chronic health condition on the basis of sex, disability, and/or another prohibited ground, this may violate § 1557.⁵⁹ This includes prescription drugs that are also used for medication abortion but are prescribed for purposes unrelated to abortion.⁶⁰

Q.10 How does the 2024 Final Rule address sex stereotypes in health care?

A. Sex stereotypes are stereotypical ideas about masculinity or femininity, such as expectations about how people should represent or communicate their gender to others. They also include gendered expectations about behaviors or roles based on sex. Sex stereotypes can reflect the belief that gender can only be binary and individuals cannot have a gender identity other than male or female. Sex stereotypes are a profound barrier to equitable access to high-quality health care and coverage for women and LGBTQI+ people. The 2024 Final Rule restores regulatory text that clarifies that § 1557 prohibits sex discrimination related to sex stereotypes. The preamble also provides examples of discrimination related to sex stereotypes, which we summarize below. Together, these measures may help deter sex discrimination based on sex stereotypes and incentivize preventive measures, such as training to recognize and address implicit gender bias in health care. They also reaffirm that patients, and particularly women and LGBTQI+ people, have legal options when they encounter related discrimination.

Sex stereotypes about women, transgender people, and nonbinary people assigned female at birth. For thousands of years, sex stereotypes have driven health care providers to discriminatorily misdiagnose women with "hysteria," an umbrella explanation crafted for a wide range of physical and behavioral symptoms that only effected people with uteruses. The American Psychiatric Association recognized hysteria as an official diagnosis until the 1980 Diagnostic and Statistical Manual of Mental Disorders. In more recent decades, health care providers have rebranded symptoms experienced by people with uteruses as "medically unexplained symptoms" and other umbrella terms.

Today, women and LGBTQI+ people, and especially people of color, are subjected to persistent sex stereotypes in health care delivery. For example, health care providers often label women, and especially Black and other women of color, "chronic complainers" and tell them that their symptoms are "all in their head."⁶⁸ As a result, women, and especially women of color, often experience years- or decades-long delays in accurate diagnosis and treatment for serious conditions.⁶⁹ For example, average estimates of diagnostic delay for people with endometriosis, a condition that nearly exclusively affects women and people assigned female at birth, range from 7–11 years.⁷⁰

Sex stereotypes also often underpin the mistreatment of women in reproductive and sexual health care and disability-related health care. Providers are also much more likely to prescribe women sedatives, rather than pain medication, for their symptoms than men.⁷¹ Because providers are half as likely to prescribe Black patients with pain medication than white patients, this discriminatory practice likely disproportionately impacts and harms Black women.⁷² In the preamble to the 2024 Final Rule, HHS recognizes that if a covered provider asserts that pain medications are not clinically appropriate for a patient based on their belief that women exaggerate and inaccurately relay information about their pain symptoms, their invocation of "clinical appropriateness" may be pretext for prohibited sex discrimination.⁷³

Sex stereotypes related to marital, family, and parental status. HHS notes in the preamble that it has settled § 1557 cases against covered entities with policies to automatically assign a man as the guarantor for his spouse's health care services when his spouse is a woman, but not automatically assign a woman spouse as the guarantor for her spouse's health care services when that spouse is a man.⁷⁴ Related policies may constitute prohibited sex discrimination related to sex stereotypes based on marital status.

For additional discussion on sex stereotypes on LGBTQI+ people, see Q&A 8.

Q.11 How does the 2024 Final Rule impact people with HIV/AIDS and other serious or chronic medical conditions?

A. Section 1557 prohibits health insurance companies from discriminating through marketing practices and benefit design. These protections are especially important for people with HIV and those with other serious or chronic conditions. For example, in 2014, the National Health Law Program (NHeLP) and The AIDS Institute filed a complaint with HHS OCR charging that four Florida health insurers discriminated against persons living with HIV/AIDS by placing all medications used in the treatment of HIV, including generics, in the highest cost sharing tiers.⁷⁵ HHS agreed, and included provisions in the 2016 Final Rule expressly prohibiting discriminatory plan benefit design and marketing.

However, the 2020 Final Rule eliminated provisions prohibiting discriminatory plan design and marketing.⁷⁶ In addition, the 2020 Final Rule also sought to exempt most private health insurance plans from § 1557's nondiscrimination protections, including protections for persons with HIV.⁷⁷ While the law still provided such protections, the rule change made it harder for persons pursuing claims of discriminatory benefit design and marketing, particularly against employer plans sold outside the ACA marketplaces.

The 2024 Final Rule restores provisions that expressly prohibit health insurers from marketing practices and benefit designs that discriminate. Under the 2024 Final Rule, coverage denials or limitations "must not be based on unlawful animus or bias, or constitute a pretext for discrimination." This clarification will help deter insurers from discriminating through benefit design and marketing, and will support health program beneficiaries, consumers, and advocates seeking to challenge discriminatory practices by insurers.

Q.12 How does the 2024 Final Rule address health care refusals based on religious or moral beliefs?

A. Federal health care refusal laws, such as the Weldon Amendment and Church Amendments, govern when and how covered entities can refuse to cover, deliver, provide information on, or offer referrals for health care services that they find objectionable based on their religious or moral beliefs. These laws contribute to dangerous barriers to essential health care for many populations who are already marginalized and underserved by our health care system. In particular, religious refusals systematically undermine or prevent access to health care for LGBTQI+ people and women, including accessing sexual, reproductive, and gender-affirming health care services such as abortion and hormone-replacement therapy. 81

The 2024 Final Rule sets forth an administrative process for covered entities to request an assurance from HHS regarding their eligibility for an exemption from certain § 1557 requirements under applicable federal health care refusal laws. 82 Covered entities may request an assurance of an exemption proactively (*i.e.*, before a § 1557 complaint is brought against them) or after a complaint is filed. 83 HHS stresses that requesting an assurance is optional; covered entities may instead rely on federal health care refusal laws. 84 HHS will grant temporary exemptions while adjudicating assurance of exemption requests. 85

In making determinations about exemptions, HHS will apply the legal standards set forth in the federal health care refusal law at issue. RHS will offer exemptions on a case-by-case basis and will not provide categorical pre-enforcement blanket exemptions. This approach will allow HHS to determine in each case whether the government has a compelling interest in denying an exemption to a particular party and, when relevant under the applicable legal standard, any harm an exemption could have on third parties, such as patients, other recipients, health care providers, and other covered entities. If a covered entity relies on a federal health care refusal exemption in denying care or coverage in good faith and HHS finds after an investigation that the entity does not satisfy the legal requirements for that exemption, the agency will not seek backward-looking relief, but will seek forward-looking relief as appropriate under the facts. The 2024 Final Rule also sets forth a process for appealing adverse decisions.

HHS's revisions to § 1557 regulations also clarify the scope of applicable federal health care refusal exemptions. In 2020, HHS amended its Title IX regulations to incorporate the Danforth Amendment (Title IX's abortion neutrality provision) and amended § 1557 regulations to specify that application could not depart from or contradict Title IX's exemptions, rights, or protections. In the 2024 Final Rule, HHS concluded as a matter of statutory interpretation that the Danforth Amendment does not apply to § 1557. It concluded this because § 1557 incorporates by reference the prohibited grounds and "enforcement mechanisms provided for and available under" enumerated civil rights laws but does not incorporate the exemptions. Further, Congress crafted the Danforth Amendment for an education context, which is fundamentally different from health care. For example, unlike educational settings such as universities in which there is more choice regarding where to enroll, "individuals often have far fewer choices when accessing health care." Health care options may be further limited by factors such as insurance coverage, the type of care sought, and the urgency of that care.

Q.13 How does the 2024 Final Rule affect individuals with limited English proficiency (LEP)?

A. Over 66 million people in the U.S. speak a language other than English at home and over 26 million households are limited English proficient. Language-related barriers may severely limit an individual's opportunity to access health care, assess options, express choices, and ask questions or seek assistance. As one recent example, the LEP population – in particular Spanish speakers and speakers of Asian and Pacific Island languages – are among the least likely to be vaccinated, and have suffered disproportionate rates of COVID-19 infections and deaths. Further, older adults who did not grow up in the United States are likely to face discrimination because they are more likely to have limited English proficiency, different mannerisms, or dress in comparison to their younger peers.

The 2024 Final Rule requires covered entities to take reasonable steps to provide meaningful access to each individual with limited English proficiency eligible or likely to be served. The 2024 Final Rule reinstates provisions from the 2016 Final Rule regarding definitions for language assistance services, limited English proficient individual, qualified interpreter, qualified translator, qualified bilingual/multilingual staff, and adds a definition of "machine translation." It also restores a number of the provisions stripped by the Trump administration including: a requirement to take reasonable steps to provide meaningful access to each LEP individual; standards for video remote interpreting; and notices to inform individuals of their rights.

The 2024 Final Rule adds a requirement that a qualified human translator must review machine translation if an entity uses machine translation for text that is critical to the:

- rights, benefits, or meaningful access of a limited English proficient individual;
- when accuracy is essential; or
- when the source documents or materials contain complex, non-literal or technical language.¹⁰²

The 2024 Final Rule also reinstates requirements to notify LEP individuals of the availability of language services. The 2016 Final Rule included requirements for "taglines" on significant documents. The 2024 Final Rule reinstated notification requirements, albeit with a new name and some changed parameters. First, HHS revised the name to "notice of availability of language assistance services and auxiliary aids and services" to cover notice to both LEP individuals and people with disabilities. Covered entities must provide the notice in English and the state's top 15 languages. They must format the notice in at least 20-point font in physical locations. Instead of requiring the taglines on all "significant"

documents as the 2016 Final Rule required, the 2024 Final Rule requires covered entities to provide this notice annually, upon request, at a conspicuous location on their website, and in a clear and prominent physical location. The notice must further appear in certain electronic and written communications including:

- notice of nondiscrimination;
- notice of privacy practices;
- application and intake forms;
- notices of denial or termination of eligibility, benefits or services (including Explanation of Benefits) and notices of appeal and grievances rights;
- communications related to a person's rights, eligibility, benefits or services that require or request a response;
- communication related to a public health emergency;
- consent forms and certain instructions related to medical procedures or operations, medical power of attorney or living will;
- discharge papers;
- communications related to the cost and payment of care including medical billing and collections materials and good faith estimates required by the No Surprises Act;
- complaint forms; and
- patient and member handbooks.¹⁰³

The 2024 Final Rule offers an "opt-out" provision if individuals want to opt out of receiving this notice, with details about how the opt-out would work including documentation of the opt-out and the individual's language and provides the notice and all materials and communications in the individual's primary language. 104

Additionally, as discussed in Q&A.4, the 2024 Final Rule applies § 1557 and Title VI of the Civil Rights Act to Medicare Part B providers. This provision is important to ensure language services are available to LEP individuals in all health care settings. For more information on the provisions related to language access, see NHeLP's <u>What is required under Title VI and Section 1557 to ensure Language Access for Individuals with Limited English Proficiency</u>.

Q.14 How does the 2024 Final Rule affect people with disabilities?

A. Prior to the ACA and §1557, disability discrimination in health insurance was simply "business as usual."¹⁰⁵ The ACA, including § 1557, sought to end discriminatory practices such as screening out individuals preexisting conditions, limiting access to behavioral health services, and using discriminatory benefit designs to exclude people with disabilities from coverage or forcing them to pay much higher health care costs. ¹⁰⁶ Section 1557 also protects against disability discrimination in health care more broadly than just insurance, ensuring that a wide array of health care entities provide non-discriminatory coverage and care.

First, the 2024 Final Rule promotes equal access to health care by requiring effective communication, including the provision of auxiliary aids and services such as qualified interpreters, note takers, real-time captioning, videophones, qualified readers, audio recordings, and Braille materials, just to name a few. Auxiliary aids and services must be provided free of charge, in accessible formats, in a timely manner, and in such a way to protect the privacy and independence of the individual with a disability. The 2024 Final Rule establishes clear standards for § 1557 procedures, including standards for requesting effective communication and reasonable accommodations.

Second, the 2024 Final Rule recognizes that § 1557 prohibits benefit designs that do not provide health insurance coverage in the most integrated setting appropriate to the needs of qualified individuals with disabilities, and prohibits practices that result in segregation or institutionalization, or the serious risk of segregation or institutionalization.¹⁰⁹

Third, the 2024 Final Rule prohibits discrimination through the use of "patient care decision support tools," including any automated or non-automated tool used to support clinical decision-making in its health programs or activities.¹¹⁰

And last, the 2024 Final Rule addresses the role of technology in providing equitable care, and includes protections regarding access in telehealth services and health related information and community technology, including mobile apps, and reiterates requirements for accessibility for buildings and facilities.¹¹¹

2024 Final Rule – Other Provisions and Effective Dates

This section includes the following questions and answers:

- Q.15 How does the 2024 Final Rule affect requirements to inform individuals of their rights?
- Q.16 How does the 2024 Final Rule affect compliance and enforcement of § 1557's protections?
- Q.17 What are some of the other notable changes in the 2024 Final Rule?
- Q.18 When is the 2024 Final Rule effective?

Q.15 How does the 2024 Final Rule affect requirements to inform individuals of their rights?

A. Civil rights protections can seem meaningless when people do not know what their rights are and how to enforce compliance. HHS indicated that it understood this in the 2016 Final Rule by requiring covered entities to post public notices so that beneficiaries, enrollees, applicants, or members of the public could know they have the right to receive health care services without discrimination. Covered entities such as hospitals and health plans were also required to provide information on grievance procedures and how to file complaints with appropriate regulators, such as OCR.

The 2020 Final Rule eliminated notice requirements, even though, as HHS acknowledged, "an unknown number of persons are likely not aware of their right to file complaints with the HHS OCR and some unknown subset of this population may suffer remediable grievances, but will not complain to OCR absent notices informing them of the process."¹¹²

The 2024 Final Rule reestablishes notice requirements so health program beneficiaries and consumers can be made aware of their rights under § 1557, as well as how to file complaints. The Final Rule requires covered entities with 15 or more employees to designate a § 1557 coordinator, establish grievance procedures, and document compliance. The rule further requires all covered entities to provide training on the civil rights policies and procedures required under the law. And a separate notice of availability must additionally outline how to specifically access language assistance services and auxiliary aids and services.

Q.16 How does the 2024 Final Rule affect compliance and enforcement of § 1557's protections?

A. The 2024 Final Rule establishes procedures for administrative enforcement actions. HHS proposes different procedures for enforcement actions that depend upon the nature of the complaint and how the entity is subject to § 1557. At the recommendation of commenters, OCR unified the procedures for filing complaints. Thus complaints against health programs and activities conducted by federal fund recipients and State Exchanges will use the procedural provisions applicable to Title VI complaints. The complaints filed against HHS, the procedural provisions for § 504 complaints apply. HHS OCR continues to serve as the primary investigatory and enforcement entity for § 1557 although OCR may refer complaints to the Equal Employment Opportunity Commission, Department of Justice, Federal Employee Health Benefits Program or other agencies if it has jurisdiction over an entity alleged to discriminate. HHS

These changes will help covered entities comply with their legal obligations under § 1557, and will also help make health program beneficiaries and consumers more aware of their rights and how to challenge unlawful discrimination.

Q.17 What are some of the other notable changes in the 2024 Final Rule?

A. The 2024 Final Rule makes other notable additions to the regulations implementing § 1557, including those described below.

Algorithms. Algorithms and other types of automated decision-making systems (ADS) play an ever-increasing role in health care eligibility and coverage determinations. 120 However, such systems are imperfect, and can lead to discriminatory determinations and may even embed discrimination. 121 The 2024 Final Rule prohibits discriminatory "patient care decision support tools," going beyond the 2022 Proposed Rule's term "clinical algorithms." 122 The 2024 Final Rule prohibits automated or augmented decision-making tools that range from flowcharts and clinical guidelines to complex computer algorithms, artificial intelligence (AI), and machine learning. The final rule also requires that covered entities have ongoing and affirmative duties to identify patient care decision support tools that use inputs, variables or factors measuring a protected characteristic and mitigate the risk of discrimination from each tool's use. For more information on this provision, see NHeLP's blog post, 1557 Final Rule Protects Against Bias in Health Care Algorithms.

OCR also seeks comments on whether it should expand this provision. Although § 1557 generally prohibits discrimination through any method, including algorithms, NHeLP would,

for example, recommend that OCR broaden the obligations of this provision to more than patient care tools and explicitly require the identification and remediation of other health care tools that affect access to care, such as eligibility systems, fraud detection tools, and data matching systems.

Telehealth. Telehealth services have greatly expanded due to the COVID-19 pandemic. As recognized in the 2022 Proposed Rule, the use of telehealth has increased access to specialists, and for some services and patient populations, has improved the patient experience. For example, the increased use of telehealth has allowed transgender individuals to access gender-affirming care without geographical constraints or fear of stigma and discrimination. However, increased reliance on telehealth may exacerbate health inequities. Low-income communities may not have access to broad band services. Furthermore, people with LEP and persons with disabilities may not be able to access or effectively use telehealth services. 124

Accordingly, the 2024 Final Rule adds a new definition of telehealth and finalizes the proposed provision to expressly prohibits discrimination in telehealth. Again, while discrimination in telehealth services already unlawful under § 1557, the 2024 Final Rule makes clear that health program beneficiaries and consumers are protected under the law.

Basis of Association. The 2024 Final Rule reinstates a provision from the 2016 Final Rule that prohibits discrimination on the basis of association with an individual with whom the individual receiving services is known to have a relationship. For example, a therapist refusing to make an appointment for a child because their parents are a Queer Non-Binary couple, or an OB-GYN refusing to provide prenatal care to a pregnant ciswoman because her doula is Transgender could constitute discrimination under the Proposed Rule.

Training. A new provision explicitly requires entities to train relevant employees on the civil rights policies and procedures outlined in the "policies and procedures" provision of the 2022 Proposed Rule. This includes general requirements, nondiscrimination policies, grievance procedures, language access procedures, effective communication procedures, and reasonable modification procedures. Covered entities must provide this training within 30 days of their implementation of the requirement to develop policies and procedures and no later than one year after the effective date of the 2024 Final Rule. For new employees, the requirement is within a "reasonable period of time" after the employee joins an entity's workforce. Entities must also document the training provided. Relevant employees include those who:

- directly encounter or interact with individuals such as patients and members of the public;
- make decisions regarding the services individuals seek from a covered entity's health programs and activities including the covered entity's executive leadership team and legal counsel; and
- perform tasks and make decisions that directly or indirectly affect patient's financial obligations including billing and collections.¹²⁸

Provisions applicable to other programs. The 2024 Final Rule restores provisions deleted in the 2020 Final Rule that protected individuals from sex discrimination in other HHS programs including marketplaces, Medicaid, CHIP (the Children's Health Insurance Program), and PACE (Program of All-Inclusive Care for the Elderly). These provisions clarify that discrimination on the basis of sex includes discrimination on the basis of sex characteristics, including intersex traits; pregnancy or related conditions; sexual orientation; gender identity and sex stereotypes.¹²⁹

Data Collection. The preamble to the 2022 Proposed Rule discusses the importance of collecting demographic data. HHS considered requiring collection of race, ethnicity, language, sex, gender, gender identity, sexual orientation, disability and age data. While HHS did not include a specific provision in the 2022 Proposed Rule or 2024 Final Rule, it reiterated that it already has the authority to require data collection to ensure compliance.¹³⁰

Q.18 When is the 2024 Final Rule effective?

A. The 2024 Final Rule is effective July 5, 2024, 60 days after its publication in the Federal Register on May 6, 2024. The 2020 Final Rule remains effective until that date. However, HHS outlined delayed compliance deadlines for certain requirements.

With regards to § 1557's prohibitions on discriminatory benefit design, most entities are covered by the 2020 Final Rule so are subject to that provision immediately. Entities newly covered under § 92.207(b)(6) must comply with this requirement by the first day of first plan year beginning on or after January 1, 2025. Notwithstanding any exceptions for benefit design, covered entities must still comply with all other provisions of the 2024 Final Rule as of the general effective dates and other specific applicability dates.

With regards to prohibitions on discrimination in health insurance and other coverage, entities who were not been subject to the 2020 Final Rule have until the first day of first plan year beginning on or after January 1, 2025 to come into compliance.

A summary of other compliance dates is as follows:

Regulatory Provision	Compliance Date
§ 92.7 Section 1557 Coordinator	Within 120 days of effective date (November 2, 2024)
§ 92.8 Policies and Procedures	Within one year of effective date (July 5, 2025)
§ 92.9 Training	Following a covered entity's implementation of the policies and procedures required by § 92.8, and no later than one year of effective date (July 5, 2025)
§ 92.10 Notice of nondiscrimination	Within 120 days of effective date (November 2, 2024)
§ 92.11 Notice of availability of language assistance services and auxiliary aids and services	Within one year of effective date (July 5, 2025)
§ 92.207(b)(1) through (5) Nondiscrimination in health insurance coverage and other health-related coverage	For health insurance coverage or other health- related coverage that was not subject to this part as of the date of publication of this rule, by the first day of the first plan year (in the individual market, policy year) beginning on or after January 1, 2025
§ 92.207(b)(6) Nondiscrimination in health insurance coverage and other health-related coverage	By the first day of the first plan year (in the individual market, policy year) beginning on or after January 1, 2025
§ 92.210(b), (c) Use of patient care decision support tools	Within 300 days of effective date (May 1, 2025)

How to Get Involved or File a Complaint

Q.19 What action can you take to support § 1557 and the 2024 Final Rule?

A. Educate yourself, your employers, your health care providers and your communities about § 1557. To ensure that the protections of § 1557 and these regulations are effectively implemented and enforced, covered entities need to understand their responsibilities and

individuals who could face discrimination need to know their rights. You can help share information about § 1557 and the 2024 Final Rule. Feel free to share this document and resources from NHeLP and other trusted sources.

Q.20 What can people do if they have experienced discrimination in a health care setting or by an insurer?

A. If an individual experiences discrimination by a provider, by an insurance company, or any entity covered by the § 1557 regulations, the individual can file a complaint with the Office for Civil Rights at HHS. They must file their complaint within 180 days of when they knew the act or omission (*e.g.*, a denial of care occurred. Individuals may also be able to file complaints with a state Insurance Commissioner, Medicaid agency, state or federal marketplace, Health Ombudsman or other state entity (depending on state law and policies). Individuals may also go to court to privately enforce their rights and stop ongoing acts of discrimination. If you are an individual who has experienced health care discrimination and need help enforcing your rights, please contact an attorney, such as your local legal services provider, or contact your state bar association for a referral.

ENDNOTES

¹ U.S. Dep't of Health & Human Servs., *Nondiscrimination in Health Programs and Activities, Final Rule*, 45 C.F.R. Part 92, 81 Fed. Reg. 31376 (May 18, 2016) (hereinafter "2016 Final Rule"), https://www.federalregister.gov/documents/2016/05/18/2016-11458/nondiscrimination-in-health-programs-and-activities.

- ² U.S. Dep't of Health & Human Servs., *Nondiscrimination in Health and Health Education Programs or Activities, Delegation of Authority*, 85 Fed. Reg. 37160 (June 19, 2020) (hereinafter "2020 Final Rule"), https://www.federalregister.gov/documents/2020/06/19/2020-11758/nondiscrimination-in-health-and-health-education-programs-or-activities-delegation-of-authority.
- ³ U.S. Dep't of Health & Human Servs., *Nondiscrimination in Health Programs and Activities*, 87 Fed. Reg. 47824 (Aug. 4, 2022) (hereinafter "2022 Proposed Rule"), https://www.federalregister.gov/documents/2022/08/04/2022-16217/nondiscrimination-in-health-programs-and-activities.
- ⁴ U.S. Dep't of Health & Human Servs., *Nondiscrimination in Health Programs and Activities, Final Rule*, (May 6, 2024) (hereinafter "2024 Final Rule"),
- https://www.federalregister.gov/documents/2024/05/06/2024-08711/nondiscrimination-in-health-programs-and-
- <u>activities#:~:text=The%20Department%20of%20Health%20and%20Human%20Services%20(HHS%20or%20the,certain%20health%20programs%20and%20activities.</u>
- ⁵ 42 U.S.C. § 18116.
- ⁶ Title VI of the Civil Rights Act of 1964 (42 U.S.C. § 2000d et seq.), Title VII of the Civil Rights Act of 1964 (42 U.S.C. § 2000e et seq.), Title IX of the Education Amendments of 1972 (20 U.S.C. § 1681 et seq.), Section 794 of Title 29, or the Age Discrimination Act of 1975 (42 U.S.C. § 6101 et seq.).
- ⁷ U.S. Dep't of Health & Human Servs., *Request for Information Regarding Nondiscrimination in Certain Health Programs or Activities*, 78 Fed. Reg. 46558 (Aug. 1, 2013); U.S. Dep't of Health & Human Servs., *Nondiscrimination in Health Programs and Activities* (Notice of Proposed Rulemaking), 80 Fed. Reg. 54172 (Sept. 8, 2015); 2016 Final Rule.

 ⁸ *See* 2020 Final Rule.
- ⁹ Shazor v. Prof'l Transit Mgmt., 744 F.3d 948, 957-58 (6th Cir. 2014).
- ¹⁰ *Id*; see also, e.g., Harris v. Maricopa County Superior Court, 631 F.3d 963, 976 (9th Cir. 2011); *Jefferies v. Harris Co. Community Action Ass'n*, 615 F.2d 1025, 1032 (5th Cir. 1980); *Lam v. University of Hawaii*, 40 F.3d 1551, 1562 (9th Cir. 1994); *Jeffers v. Thompson*, 264 F. Supp. 3d 314, 326 (D. Md. 2003).
- ¹¹ 2024 Final Rule § 92.101(a).
- ¹² 42 U.S.C. § 18116(a); 2024 Final Rule §§ 92.2(a), 92.4.
- ¹³ 2024 Final Rule § 92.4 (defining "covered entity" and "health program or activity").
- ¹⁴ See 2024 Final Rule §§ 92.2, 92.4, 92.207.
- ¹⁵ See 2024 Final Rule § 92.207, 89 Fed. Reg. 37617–37624.
- ¹⁶ 42 U.S.C. § 18116(a).
- ¹⁷ See 89 Fed. Reg. at 37666.

- ¹⁸ See Part II., Reasons for the Proposed Rulemaking, 87 Fed. Reg. 47829-47837.
- ¹⁹ Bostock v. Clayton County, 140 S.Ct. 1731 (2020), available at https://www.supremecourt.gov/opinions/19pdf/17-1618 hfci.pdf.
- ²⁰ HHS, HHS Announces Prohibition on Sex Discrimination Includes Discrimination on the Basis of Sexual Orientation and Gender Identity (May 10, 2021),

https://www.hhs.gov/about/news/2021/05/10/hhs-announces-prohibition-sex-discrimination-includes-discrimination-basis-sexual-orientation-gender-identity.html.

- ²¹ See, e.g., E.O. 13985, 86 Fed. Reg. 7009 (2021); E.O. 13988, 86 Fed. Reg. 7023 (2021);
 E.O. 13995, 86 Fed. Reg. 7193 (2021); Memorandum on Redressing Our Nation's and the Federal Government's History of Discriminatory Housing Practices and Policies (2021), <a href="https://www.whitehouse.gov/briefing-room/presidential-actions/2021/01/26/memorandum-on-redressing-our-nations-andthe-federal-governments-history-of-discriminatory-housing-practices-and-policies/; Memorandum on Condemning and Combating Racism, Xenophobia, and Intolerance Against Asian Americans and Pacific Islanders in the United States (2021), https://www.whitehouse.gov/briefing-room/presidential-actions/2021/01/26/memorandum-condemning-and-combatingracism-xenophobia-and-intolerance-against-asian-americans-and-pacific-islanders-in-the-united-states/; E.O. 14012, 86 Fed. Reg. 8722 (2021); E.O.14031, 86 Fed. Reg. 29675 (2021); E.O. 14035, 86 Fed. Reg. 34593 (2021); E.O. 14041, 86 Fed. Reg. 50443 (2021); E.O.14045, 86 Fed. Reg. 51581 (2021); and other Presidential Actions.
 ²² HHS, HHS Announces Prohibition on Sex Discrimination Includes Discrimination on the Basis of Sexual Orientation and Gender Identity (May 10, 2021),
- https://www.hhs.gov/about/news/2021/05/10/hhs-announces-prohibition-sex-discrimination-includes-discrimination-basis-sexual-orientation-gender-identity.html.
- ²³ Madeline T. Morcelle, Nat'l Health Law Prog., *How Proposed Changes to Section 1557 Strengthen Protections Related to Pregnancy or Related Conditions, Including Abortion* (Sep. 27, 2022), https://healthlaw.org/how-proposed-changes-to-section-1557-strengthen-protections-related-to-pregnancy-or-related-conditions-including-abortion/.
- ²⁴ 2016 Final Rule, *supra* note 1, § 92.4; 2020 Final Rule, *supra* note 2.
- ²⁵ 2024 Final Rule § 92.101(a)(2); see also 89 Fed. Reg. 37575 (stressing that the grounds enumerated in this section are not an exhaustive list of what constitutes sex discrimination under § 92.101(a)(2)).
- ²⁶ 2016 Final Rule, *supra* note 1, at 31390, § 92.4 ("On the basis of sex includes, but is not limited to, discrimination on the basis of pregnancy, false pregnancy, termination of pregnancy, or recovery therefrom, childbirth or related medical conditions, sex stereotyping, and gender identity.").
- ²⁷ 2024 Final Rule §§ 92.206, 92.208.
- ²⁸ 2024 Final Rule § 92.101(a)(2).
- ²⁹ 89 Fed. Reg. 37573.
- ³⁰ See Bostock, supra note 19.
- 31 2024 Final Rule § 92.101(a)(2).
- 32 2024 Final Rule § 92.101(a)(2)(iii).
- 33 2024 Final Rule § 92.101(a)(2)(iv).
- ³⁴ 2024 Final Rule § 92.101(a)(2)(i).
- ³⁵ 2024 Final Rule § 92.206.
- ³⁶ 2024 Final Rule §§ 92.206(b)(4), 92.207(b)(4)-(5).

- ³⁷ 2024 Final Rule § 92.207(b)(4)–(5).
- ³⁸ 2024 Final Rule § 92.208.
- ³⁹ 2024 Final Rule § 92.101(a)(2)(ii).
- ⁴⁰ 2024 Final Rule, *supra* note 4, at 37634.
- ⁴¹ 2016 Final Rule, *supra* note 1, § 92.4.
- ⁴² Franciscan All., Inc. v. Burwell, 227 F. Supp. 3d 660 (N.D. Tex. 2016); Franciscan All., Inc.
- v. Azar, 414 F. Supp. 3d 928 (N.D. Tex. 2019).
- ⁴³ 2020 Final Rule, *supra* note 2, at 35720.
- ⁴⁴ Franciscan All., Inc. v. Becerra, 553 F. Supp. 3d 361 (N.D. Tex. 2021), amended, No. 7:16–cv–00108–O, 2021 WL 6774686 (N.D. Tex. Oct. 1, 2021), appeal pending, No. 21–11174 (5th Cir. Nov. 21, 2021).
- ⁴⁵ 2024 Final Rule, *supra* note 4, at 37576 ("we agree that protections for pregnancy or related conditions include termination of pregnancy").
- ⁴⁶ *Id.*, at 37634.
- ⁴⁷ *Id.*, at 37676.
- ⁴⁸ *Id*.
- ⁴⁹ *Id.* at 37669.
- ⁵⁰ *Id.*, at 37635.
- ⁵¹ Saraswathi Vedam et al., *The Giving Voice to Mothers Study: Inequity and Mistreatment During Pregnancy and Childbirth in the United States*, 16(77) Reproductive Health (June 11, 2019), https://reproductive-health-journal.biomedcentral.com/articles/10.1186/s12978-019-0729-2.
- ⁵² Carol Sakala et al., National Partnership for Women & Families, *Listening to Mothers in California: A Population-Based Survey of Women's Childbearing Experiences, Full Survey Report*, 64–65 (2018), https://www.chcf.org/wp-content/uploads/2018/09/ListeningMothersCAFullSurveyReport2018.pdf.
- ⁵³ 2024 Final Rule, *supra* note 4, at 37595.
- ⁵⁴ 2024 Final Rule, *supra* note 4, at 37577.
- ⁵⁵ Dobbs v. Jackson Women's Health Organization, 142 S. Ct. 2228 (2022); Madeline T. Morcelle, Nat'l Health Law Prog., HHS Addresses Post-Dobbs Barriers to Care for Chronic Health Conditions Through Section 1557 of the ACA (May 2, 2024), https://healthlaw.org/hhs-addresses-post-dobbs-barriers-to-care-for-chronic-health-conditions-through-section-1557-of-the-aca/ (last visited May 4, 2024).
- ⁵⁶ See., e.g., Rebecca Flood, Anger as Woman Denied 'Abortifacient' Medication After Roe v. Wade Ruling, Newsweek (Jul. 4, 2022), https://www.newsweek.com/anger-woman-denied-abortifacient-medication-roe-v-wade-abortion-1721428; Kylie Cheung, Woman with Severe Chronic Pain Was Denied Medication for Being 'Childbearing Age,' Jezebel (Sep. 22, 2022), https://jezebel.com/woman-with-severe-chronic-pain-was-denied-medication-fo-1849569187.
- ⁵⁷ See, e.g., Liz Plank, Abortion Bans are Stopping These Women from Getting Medication for their Chronic Illness, MSNBC (Jul. 11, 2022), https://www.msnbc.com/opinion/msnbc-opinion/post-roe-abortions-aren-t-only-healthcare-being-denied-women-n1296928.
- ⁵⁸ See, e.g., Alisa Reznick, *Abortion bans have made some medicines harder to get. The Biden administration is pushing back*, KJZZ (Oct. 11, 2022),
- https://kjzz.org/content/1816570/abortion-bans-have-made-some-medicines-harder-get-biden-administration-pushing-back; Giulia Carbonaro, *Arizona Teen Denied Lifesaving Questions and Answers on the 2024 Final Rule Addressing Nondiscrimination Protections under the ACA's Section 1557*

Medication Due to State's Abortion Ban, Newsweek (Oct. 3, 2022),

https://www.newsweek.com/arizona-teen-denied-life-saving-medication-state-abortion-ban-1748264.

- ⁵⁹ 2024 Final Rule, *supra* note 4, at 37606, 37636; *see also* HHS, Guidance to Nation's Retail Pharmacies: Obligations under Federal Civil Rights Laws to Ensure Nondiscriminatory Access to Health Care at Pharmacies (Revised Sept. 2023), https://www.hhs.gov/civil-rights/for-individuals/special-topics/reproductive-healthcare/pharmacies-guidance/index.html (last visited May 4, 2024).
- ⁶⁰ 2024 Final Rule, *supra* note 4, at 37606.
- ⁶¹ Madeline T. Morcelle, Nat'l Health Law Prog., *How the Proposed Section 1557 Rule Addresses Discrimination Based on Sex Stereotypes* (Sept. 27, 2022), https://healthlaw.org/how-the-proposed-section-1557-rule-addresses-discrimination-based-on-sex-stereotypes-2/.
- ⁶² See 81 Fed. Reg 31392.
- 63 2024 Final Rule § 92.101(a)(2)(v).
- ⁶⁴ See, e.g., Katrina Hui, et al., *Recognizing and Addressing Implicit Gender Bias in Medicine*, 192(42) CMAJ E1269 (2020), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7588202/.
- 65 See, e.g., McGill U. Off. Of Science & Society, *The History of Hysteria*, https://www.mcgill.ca/oss/article/history-quackery/history-hysteria.
- ⁶⁶ *Id*.
- ⁶⁷ Anushay Hossain, *The Pain Gap: How Sexism and Racism in Healthcare Kill Women* 47 (2021).
- ⁶⁸ *Id.* at 46; Vidya Rao, *'You Are Not Listening To Me': Black Women on Pain And Implicit Bias in Medicine*, TODAY (Jul. 2020), https://www.today.com/health/implicit-bias-medicine-how-it-hurts-black-women-t187866; Nat'l Pain Report, Women in Pain Survey (2014), https://www.surveymonkey.com/results/SM-P5J5P29L/ (finding that 45% percent of women with chronic pain surveyed had been told by a health care provider that their pain was in their head).
- ⁶⁹ Hossain, *supra* note 67, at 46–47.
- ⁷⁰ Omar T. Sims, *Stigma and Endometriosis: A Brief Overview and Recommendations to Improve Psychosocial Well-Being and Diagnostic Delay*, 18(15) Int. J. Environ. Res. Pub. Health 8210 (2021).
- ⁷¹ Laura Kiesel, *Women and Pain: Disparities in Experience and Treatment*, Harvard Health Blog (Oct. 2017), https://www.health.harvard.edu/blog/women-and-pain-disparities-in-experience-and-treatment-2017100912562.
- ⁷² Astha Signhal et al., *Racial-Ethnic Disparities in Opioid Prescriptions at Emergency Department Visits for Conditions Commonly Associated with Prescription Drug Abuse*, PLOS ONE (Aug. 2016),

https://journals.plos.org/plosone/article?id=10.1371%2Fjournal.pone.0159224.

- ⁷³ 2024 Final Rule, *supra* note 4, at 37598.
- ⁷⁴ *Id*. at 37632.
- ⁷⁵ Nat'l Health Law Program & The AIDS Inst., *Re: Discriminatory Pharmacy Benefits Design in Select Qualified Health Plans Offered in Florida, Administrative Complaint*, filed with the HHS Office for Civil Rights (May 28, 2014), https://healthlaw.org/resource/nhelp-and-the-aids-institute-complaint-to-hhs-re-hiv-aids-discrimination-by-fl/.

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- ⁷⁶ This provision was § 92.207 in the 2016 Final Rule.
- ⁷⁷ 2020 Final Rule § 92.3(c).
- ⁷⁸ 2024 Final Rule § 92.207.
- ⁷⁹ 2024 Final Rule § 92.207(c).
- ⁸⁰ See, e.g., 2 U.S.C. § 300a-7 et seq; Madeline T. Morcelle & Charly Gilfoil, Nat'l Health Law Prog., HHS's Final Rule on Health Care Refusals: What Health Advocates Need to Know 1 (Jan. 24, 2024), https://healthlaw.org/resource/hhss-2024-final-rule-on-health-care-refusals-what-health-advocates-need-to-know/.
- ⁸¹ See, e.g., Amy Chen & Hayley Penan, Nat'l Health Law Prog., Health Care Refusals & How They Undermine Standards of Care Part II: The Impact of Health Care Refusals, Discrimination, and Mistreatment on LGBTQ Patients and Families (Jun. 13, 2022), https://healthlaw.org/health-care-refusals-discrimination-and-mistreament-on-lgbtq-patients-and-families;; Shabab Ahmed Mirza & Caitlin Rooney, Ctr. Am. Prog., Discrimination Prevents LGBTQ People From Accessing Health Care (2018), https://www.americanprogress.org/article/discrimination-prevents-lgbtq-people-accessing-health-care.
- ⁸² 2024 Final Rule § 92.302.
- 83 2024 Final Rule, *supra* note 4, at 37656.
- 84 2024 Final Rule § 92.302(a), 89 Fed. Reg. at 37647.
- ⁸⁵ 2024 Final Rule § 92.302(b), 89 Fed. Reg. at 37648 (describing slight variations in temporary exemptions depending on whether a request is submitted prior to any administrative investigation and enforcement or during an investigation).
- 86 *Id.*; *see, e.g.*, 42 U.S.C. 2000bb–1(b) (providing that the federal government may not substantially burden a person's exercise of religion unless "it demonstrates that application of the burden to the person (1) is in furtherance of a compelling governmental interest; and (2) is the least restrictive means of furthering that compelling governmental interest.").
- 87 2024 Final Rule, *supra* note 4, at 37656.
- ⁸⁸ *Id*. at 37656–37657.
- ⁸⁹ *Id*. at 37647.
- ⁹⁰ *Id*. § 93.302(e).
- ⁹¹ 20 U.S.C. § 1688 (2012) (The Danforth Amendment reads that "Nothing in this chapter shall be construed to require or prohibit any person . . . to provide or pay for any benefit or service . . . related to an abortion."); 87 Fed. Reg. at 47879; *Franciscan All., Inc. v. Burwell*, 227 F. Supp. 3d 660 (N.D. Tex. 2016); 2020 Final Rule, *supra* note 2, at 37160.
- ⁹² 2024 Final Rule, *supra* note 4, at 37576.
- ⁹³ 42 U.S.C. 18116(a); 2024 Final Rule, *supra* note 4, at 37637.
- ⁹⁴ *Id*.
- ⁹⁵ *Id*. at 37532.
- ⁹⁶ *Id*. at 37637.
- ⁹⁷ American Community Survey, 2020, *Table S1601, Language Spoken at Home, American Community Survey 5-Year Estimates*,

https://data.census.gov/cedsci/table?q=S1601&tid=ACSST5Y2020.S1601; Table S1602, Limited English Speaking Households, American Community Survey, 5-Year Estimates, https://data.census.gov/cedsci/table?q=S1602&tid=ACSST5Y2020.S1602.

⁹⁸ A report in the *Honolulu Star Advertiser* documents low rates of vaccinations among Hawai'ians and Asia-Pacific Islanders in Hawai'i. Jayna Omaye, *Hawaii Officials Step Up Efforts to COVID-19 Vaccine Access to Underserved Communities*, STAR ADVERTISER (Jun. 8, 2021), https://www.staradvertiser.com/2021/06/08/hawaii-news/officials-step-up-efforts-to-expand-covid-19-vaccine-access-to-underserved-communities/. This was also documented by Slate and Kaiser Health News. Richard Salame, *Limited English Skills Can Mean Limited Access to the COVID-19 Vaccine*, SLATE (Apr. 30, 2021), https://slate.com/news-and-politics/2021/04/covid-19-vaccine-for-non-english-speakers.html; Rachana Pradhan, '*Press 1 for English': Vaccination Sign-Ups Prove Daunting for Speakers of Other Languages*, KFF HEALTH NEWS (Mar. 23, 2021), https://khn.org/news/article/press-1-for-english-vaccination-sign-ups-prove-daunting-for-speakers-of-other-languages/.

⁹⁹ The Leadership Conference on Civil & Human Rights, *Comments in Response to Proposed Religious Refusal Rule*, (Mar. 2018), https://civilrights.org/resource/comments-response-proposed-hhs-religious-refusal-rule/#_edn35.

¹⁰⁰ 2024 Final Rule §§ 92.201–92.204; *See also*, Jane Perkins, et al., Nat'l. Health Law Program, *Highlights of the Section 1557 Final Rule* (May 16, 2016), https://healthlaw.org/resource/issue-brief-highlights-of-the-section-1557-final-rule/.

¹⁰¹ 2024 Final Rule § 92.4.

¹⁰² *Id*.

¹⁰³ 2024 Final Rule § 92.11(c)(5).

¹⁰⁴ 2024 Final Rule § 92.11(d).

¹⁰⁵ See generally, e.g. Brief for Nat'l Health Law Prog. & Disability Rights California as Amicus Curiae Supporting Respondents, *CVS Pharmacy, Inc. v. Doe,* 141 S.Ct. 2882 (2021); Valarie K. Blake, *An Opening for Civil Rights in Health Insurance After the Affordable Care Act,* 36 B.C. J.L. & Soc. Just. 235 (2016) (describing pre-ACA health insurance discrimination and how the ACA addressed those issues); Sara Rosenbaum et al., *Crossing the Rubicon: The Impact of the Affordable Care Act on the Content of Insurance Coverage for Persons with Disabilities,* 25 Notre Dame J. L. Ethics & Pub. Pol'y 235 (2014) (describing ACA nondiscrimination provisions and focusing on the function of essential health benefits).

¹⁰⁶ 42 U.S.C. §§ 300gg–4(a)(8) (prohibiting discrimination in insurance regarding eligibility or coverage based on disability); 300gg-11 (prohibiting lifetime limits); 300gg-6 and 18022 (requiring health insurance to be "comprehensive") and including behavioral health as an "essential health benefit."

¹⁰⁷ Final Rule § 92.202.

¹⁰⁸ Final Rule §§ 92.7–92.8.

¹⁰⁹ Final Rule § 92.207(b)(6).

Final Rule 92.210; Cassandra LaRose and Elizabeth Edwards, Nat'l Health Law Prog., 1557 Final Rule Protects Against Bias in Health Care Algorithms (May 1, 2024),

https://healthlaw.org/1557-final-rule-protects-against-bias-in-health-care-algorithms/.

¹¹¹ Final Rule §§ 92.204(b); 92.211; 92.203.

¹¹² 84 Fed. Reg. 27883.

¹¹³ 2024 Final Rule § 92.10.

¹¹⁴ 2024 Final Rule § 92.7.

¹¹⁵ 2024 Final Rule § 92.9.

¹¹⁶ 2024 Final Rule § 92.11.

Questions and Answers on the 2024 Final Rule Addressing Nondiscrimination Protections under the ACA's Section 1557

- ¹¹⁷ 2024 Final Rule § 92.303(a).
- ¹¹⁸ 2024 Final Rule § 92.304(a).
- ¹¹⁹ See 89 Fed. Reg. at 37637.
- ¹²⁰ See generally Benefits Tech Advisory Hub, https://www.btah.org/.
- ¹²¹ See *e.g.*, NHeLP Comments to the HHS Agency for Healthcare Research and Quality, Request for Information on the Use of Clinical Algorithms That Have the Potential To Introduce Racial/Ethnic Bias Into Healthcare Delivery (June 10, 2021),

https://healthlaw.org/resource/nhelp-ahrq-comments/.

- ¹²² 2024 Final Rule § 92.210.
- ¹²³ See 87 Fed. Reg. 47884.
- ¹²⁴ See NHeLP, Medicaid Principles on Telehealth, (May 11, 2020),

https://healthlaw.org/resource/medicaid-principles-on-telehealth//

- ¹²⁵ 2024 Final Rule §§ 92.4, 92.211.
- ¹²⁶ 2024 Final Rule § 92.209.
- ¹²⁷ 2024 Final Rule § 92.9(b)(1), (2).
- ¹²⁸ 2024 Final Rule § 92.9(b)(4).
- ¹²⁹ 2024 Final Rule 42 C.F.R. §§ 438.3, 438.206, 440.262, 457.495, 460.98, 460.112; 45 C.F.R.
- §§ 147.104, 155.120, 155.220, 156.125, 156.200, 156.1230.
- ¹³⁰ 89 Fed. Reg. 37549, 37571.