



Women's Law Project

October 3, 2022

Secretary Xavier Becerra
U.S. Department of Health and Human Services
Herbert H. Humphrey Building, Room 509F
200 Independence Avenue SW
Washington, DC 20201

RE: Docket ID HHS-OS-2022-0012, RIN 0945-AA17, Nondiscrimination in Health and Health Education Programs or Activities

Dear Secretary Becerra:

The Women's Law Project ("WLP") submits these comments in response to the Department of Health and Human Services' ("the Department's") and the Office for Civil Rights' ("OCR's") proposed rule changes on "Nondiscrimination in Health Programs and Activities" (Section 1557), published in the Federal Register on August 4, 2022.¹

WLP is a public interest law center with offices in Philadelphia and Pittsburgh, Pennsylvania. Founded in 1974, WLP is dedicated to creating a more just and equitable society by advancing the rights and status of all women, girls, and LGBTQI+ people in Pennsylvania and beyond. We leverage impact litigation, policy advocacy, public education, and direct legal assistance and representation to dismantle discriminatory laws, policies, and practices and eradicate institutional biases and unfair treatment based on sex or gender. WLP believes that all people should have access to health care for themselves and their families without fear of discrimination.

WLP strongly supports the Proposed Rule because it restores and expands the scope of Section 1557 protections along many axes and will have a significant, positive impact on the health and well-being of the communities we serve. Specifically, the Proposed Rule will provide necessary access to health care for people seeking reproductive health care, LGBTQI+ people, people living with disabilities, and people whose primary language is not English. The proposed changes would remove barriers to accessing adequate health care, which disproportionately impact those living at the intersections of marginalized identities. These updates are necessary to redress the disastrous incapacitation of Section 1557 protections in the Trump Administration's 2020 Rule—to which WLP submitted a comment with several objections.² Furthermore, the Proposed Rule provides needed protections following the Supreme Court's devastating decision in *Dobbs v. Jackson Women's Health Organization*³ and ongoing attacks on transgender and

¹ Nondiscrimination in Health Programs and Activities, 87 Fed. Reg. 47824 (Aug. 4, 2022) (amending 42 C.F.R. §§ 91, 92, 93).

² Mashayla Hays, *RE: Docket ID HHS-OCR-2019-0007, RIN 0945-AA11, Nondiscrimination in Health and Health Education Programs or Activities*, WOMEN'S LAW PROJECT (Aug. 13, 2019), <https://www.regulations.gov/comment/HHS-OCR-2019-0007-145461> (2020 proposed rule weakens Section 1557 protections to the detriment of vulnerable communities including women of color, LGBTQI+ people, people with limited English proficiency, immigrants, and people living with disabilities).

³ *Dobbs v. Jackson Women's Health Org.*, 142 S. Ct. 2228, 2242 (2022) (overturning *Roe v. Wade*, 410 U.S. 113 (1973) and *Planned Parenthood of Southeastern Pa. v. Casey*, 505 U.S. 833 (1992)).

nonbinary individuals. We urge the Department to recognize the ways discrimination in health care can appear in people’s lives and to make explicit the strong federal protections against discrimination.

I. THE DEPARTMENT UPDATES THE SCOPE OF SECTION 1557 IN THE PROPOSED RULE.

a. The Proposed Rule correctly restores the scope of Section 1557 protections against discrimination.

Section 1557 of the ACA is a landmark civil rights law that prohibits discrimination based on race, color, national origin, sex, age and disability in health care. Yet, the 2020 Rule limited the law’s reach in two significant ways. First, clear statutory language provides that Section 1557’s discrimination prohibitions apply to covered programs and activities that are “administered by an Executive Agency *or* any entity established under this title.”⁴ But the 2020 Rule applies to “any program or activity administered by the Department under Title I of the [ACA].”⁵ The Department correctly construes “or” to distinguish programs and activities administered by an Executive Agency from those operated by a Title I entity. As such, unlike the 2020 Rule which narrowly applies to programs and activities by the Department *under Title I of the ACA*, the Proposed Rule applies to “every health program or activity administered by the Department.”⁶ Second, the 2020 Rule also exempted most health insurance plans from Section 1557.⁷ However, Section 1557 identifies three examples of federal financial assistance which all pertain to health insurance. Further, Congress’ intent that Section 1557 applies to health insurance is demonstrated by the fact that Section 1557 is contained within the ACA, a law that predominately regulates health insurance. The Department correctly believes the 2020 Rule limits application to health insurance in a manner inconsistent with the statute and Congressional intent.

The Proposed Rule restores regulations that recognize Section 1557’s applicability to federal health care programs, the ACA’s state and federal Marketplaces and the plans sold through them, as well as other commercial health plans if the insurer receives federal financial assistance.⁸ The restoration of Section 1557’s scope is important because a limited reach of Section 1557’s protection is especially harmful to communities who already face systemic barriers accessing health care. For example, LGBTQI+ communities commonly face insurance-related obstacles such as coverage exclusions and lack of facilities offering services for LGTQI+ clients to obtain adequate health care.⁹ As reflected in the National Health Interview Survey, LGBTQI+ individuals are more likely than their non-LGBTQI+ counterparts to report delaying care, less likely to have a usual source of care, and more likely to be concerned about medical bills.¹⁰ The fact that a relatively high percentage of the LGBTQI+ population delay counseling due to cost is concerning given that individuals in these communities face higher rates of multiple forms of violence and would benefit from counseling.¹¹

⁴ 42 U.S.C. § 18116(a).

⁵ 45 C.F.R. §92.3(a)(2) (2022).

⁶ 87 Fed. Reg. at 47838.

⁷ 45 C.F.R. § 92.3(c) (2022).

⁸ 87 Fed. Reg. at 47838, 47842, 47868.

⁹ Arielle Bosworth et al., *Health Insurance Coverage and Access to Care for LGBTQ+ Individuals: Current Trends and Key Challenges*, OFFICE OF HEALTH POL’Y 4 & 9 (June 2021), <https://aspe.hhs.gov/sites/default/files/2021-07/lgbt-health-ib.pdf>.

¹⁰ *Id.* at 8.

¹¹ Jill S. Levenson et al., *Trauma-informed and Affirmative Mental Health Practices with LGBTQ+ Clients*, 4 PSYCH. SERVICES 1, 1 (2021).

b. WLP supports Proposed Rule’s expansion of Section 1557’s scope to include Medicare Part B and telehealth services.

The Proposed Rule treats Medicare Part B payments as federal financial assistance, and Part B providers and suppliers as recipients under Section 1557. This clarification by the Proposed Rule is especially important for older adults and people with disabilities as Medicare Part B provides essential coverage, including preventative care, durable medical equipment, mental health and substance use disorder treatment. Also, the clarification is important for individuals with limited English proficiency to ensure language access services are available for services provided solely through Medicare Part B are used to deliver care.

The Proposed Rule recognizes the increased use and potential of telehealth and adds a new regulation that expressly prohibits discrimination in telehealth making clear that health program beneficiaries and consumers are protected under the law. The COVID-19 pandemic saw a dramatic rise in the use of telehealth services. For example, one study during the pandemic found that medication abortions provided via telehealth services were just as effective and safe as medication abortions provided in a clinic.¹² In the context of reproductive and sexual health care, where privacy, timeliness and discretion are important, telehealth has provided greater access to specialist care. While telehealth services offer a host of advantages, the potential for telehealth to minimize health inequities is lost if telehealth providers fail to consider barriers like language, lack of internet access, or lack of adaptive equipment.¹³ As such, strong federal protection against discrimination is especially important when telehealth services are used to deliver care.

c. WLP supports the Department’s proposal to repeal the Danforth Amendment to Section 1557.

Health care refusals on religious based objections raised by healthcare providers remain a troubling reality for many populations who already face health disparities. The U.S. Supreme Court decision in *Burwell v. Hobby Lobby* expanded the Religious Freedom Restoration Act leaving it vulnerable to misuse and as a way to discriminate against people of color, women, and the LGBTQI+ community. Religious refusals limit access to health care for LGBTQI+ people and women, including access to sexual and reproductive health services such as abortion and gender-affirming care, and exacerbate health inequities. In thirty-three states including Pennsylvania, women of color are disproportionately more likely to give birth at a Catholic hospital and consequently denied access to many facets of comprehensive sexual and reproductive health care.¹⁴ This is especially concerning given that women of color already face serious health disparities including high rates of infant and maternal mortality. For example, from 2011 to 2016, Black women in Pennsylvania died from pregnancy and childbirth at a rate more than three times that of

¹² Erica Chong et al., *Expansion of a Direct-to-patient Telemedicine Abortion Service in the United States and Experience during the COVID-19 Pandemic*, 1 *CONTRACEPTION* 104:43-48 (July 2021).

¹³ U.S. Dep’t of Health and Hum. Services, *Health Equity in Telehealth*, <https://telehealth.hhs.gov/providers/health-equity-in-telehealth/#health-equity-for-special-populations> (last visited Sep. 28, 2022).

¹⁴ Kira Shepherd et al., *Bearing Faith: The Limits of Catholic Health Care for Women of Color*, *PUBL. RTS/PRIV. CONSCIENCE PROJECT AND PUB. HEALTH SOL.* 13 (2018), <https://lawrightsreligion.law.columbia.edu/sites/default/files/content/BearingFaith.pdf>.

white women.¹⁵ Black women in Philadelphia represent seventy-three percent of pregnancy-related deaths.¹⁶

In 2020, the Department applied the Title IX religious refusals exception and abortion exception, commonly referred to as the Danforth Amendment, to Section 1557. Application of these provisions via the 2020 rule has been enjoined in courts because of the application's life-threatening implications. It is material that the Proposed Rule seeks to repeal the 2020 Rule's application of the Danforth Amendment to Section 1557.¹⁷

Neither the 2016 nor the 2020 Rules provided specific procedures for recipients to raise religious- or conscience-based concerns. The Proposed Rule makes clear there is no blanket exemption from its provisions for religious entities. Instead, it establishes procedures whereby recipients may raise concerns. An entity that wishes to assert an exemption would submit a request to the OCR. The OCR will then engage in a "fact-sensitive, case-by-case analysis" to determine whether the covered entity is entitled to an exemption from provisions of the rule.¹⁸ The OCR's analysis will "account for any harm an exemption could have on third parties."¹⁹

Although the OCR is obligated to conduct an inquiry into each request for a religious exemption, its determination should not be unduly delayed because people harmed by healthcare discrimination often deal with increased negative health outcomes or have been forced to forgo care entirely. In the context of reproductive health, abortion care is time-sensitive per se, but even more so now as state abortion laws changing day-by-day cast legal uncertainty. The Turnaway Study shows that women experienced various degrees and types of harm from being denied a wanted abortion because they were past the gestational limit.²⁰ Women denied wanted abortions were more likely to experience serious complications from the end of pregnancy including eclampsia and death, more likely to stay tethered to abusive partners, more likely to suffer anxiety and loss of self-esteem in the short term after being denied abortion, more likely to experience physical health complications, and less likely to have aspirational life plans for the coming year.²¹ Additionally, patients should be aware of their options when deciding which institution to receive care from. As such, it is important that the OCR considers the contexts in which requests for religious exemptions are asked for and make those determinations public so people seeking care are aware if an entity does or does not provide the health care services they need.

II. THE PROPOSED RULE RECOGNIZES VARIOUS FORMS OF SEX DISCRIMINATION BY RESTORING THE DEFINITION OF "ON THE BASIS OF SEX" TO PROTECT AGAINST SPECIFIC FORMS OF DISCRIMINATION, INCLUDING PREGNANCY

¹⁵ Office of Health Equity, *The State of Health Equity in Pennsylvania* 14 (Jan. 2019), <https://www.health.pa.gov/topics/Documents/Health%20Equity/The%20State%20of%20Health%20Equity%20in%20PA%20Report%20FINAL.pdf>.

¹⁶ Sojourner Ahébé, *'They Were Dying After They Went Home': Black Women in Philly Represent 73% of Pregnancy-Related Deaths*, WHY?Y (Apr. 3, 2021), <https://why.org/articles/they-were-dying-after-they-went-home-black-women-in-philly-represent-73-of-pregnancy-related-deaths/>.

¹⁷ 87 Fed. Reg. at 47878-79.

¹⁸ 87 Fed. Reg. at 47841.

¹⁹ 87 Fed. Reg. at 47886.

²⁰ ADVANCING NEW STANDARDS IN REPROD. HEALTH, *Turnaway Study*, <https://www.ansirh.org/research/ongoing/turnaway-study> (last visited Sept. 9, 2022); see DIANA GREENE FOSTER, THE TURNAWAY STUDY (2020).

²¹ *Id.*

STATUS, SEX STEREOTYPES, SEX CHARACTERISTICS, SEXUAL ORIENTATION, AND GENDER IDENTITY.

The Proposed Rule restores the definition of “on the basis of sex” to include sexual orientation, gender identity, sex stereotypes, and sex characteristics—including intersex traits, and pregnancy status—including pregnancy termination.²² The updated definition includes the nexus of any ground upon which discrimination is prohibited—including the broad definition of sex—and marital, familial, and parental status.²³ These updates are vital because they protect vulnerable populations and people associated with vulnerable populations—such as the child of a same-sex couple—and show consistency with the Supreme Court holding in *Bostock v. Clayton County*²⁴ and *Price Waterhouse v. Hopkins*.²⁵ However, to ensure adherence to Section 1557, these updates should be expanded to further bolster protections against discrimination on the basis of LGBTQ+ status and pregnancy termination.

a. The Final Rule should explicitly include “transgender status” in the definition of “on the basis of sex.”

LGBTQI+ people “face pervasive health disparities and barriers in accessing needed health care”²⁶ which have resulted in considerable health inequalities.²⁷ LGBTQI+ people report poorer health overall and are at increased risk of numerous health conditions such as sexually transmitted infections, HIV, obesity, substance use disorder, and mental health conditions including suicidality.²⁸

Peer review studies show a correlation between this inequality and health care related discrimination. Per a 2010 report addressing health care discrimination against LGBT people and people living with HIV, more than half of all respondents experienced “at least one of the following types of discrimination in health care: being refused needed care; health care professionals refusing to touch them or using excessive precautions; health care professionals using harsh or abusive language; being blamed for their health care status; or health care professionals being physically rough or abusive.”²⁹ The same report

²² 87 Fed. Reg. at 47826.

²³ 87 Fed. Reg. at 47878.

²⁴ *Bostock v. Clayton County*, 590 U.S. ___, 140 S. Ct. 1731 (2020) (finding discrimination per sexual orientation or gender identity to be prohibited discrimination on the basis of sex).

²⁵ *Price Waterhouse v. Hopkins*, 490 U.S. 228 (1989) (finding discrimination on the basis of sex includes sex stereotyping which is expecting some to act, dress, and/or behave in a manner coincident with stereotypes of people of the same sex).

²⁶ 87 Fed. Reg. at 47833-35.

²⁷ NATIONAL ACADEMIES OF SCIENCES, ENGINEERING, AND MEDICINE, UNDERSTANDING THE WELL-BEING OF LGBTQI+ POPULATIONS at 287-361 (2020), <https://nap.nationalacademies.org/catalog/25877/understanding-the-well-being-of-lgbtqi-populations> (LGBTQI+ people “encounter barriers to health care services . . . include[ing] individual factors, such as health literacy; interpersonal factors, such as individual experiences of discrimination by health care providers and insurers; and broader structural factors, such as lower rates of health insurance coverage and higher rates of poverty among [LGBT] communities and households headed by same-sex couples, which puts health care financially out of reach for many. Another common barrier is a widespread lack of training for providers . . . which means that many individuals, particularly transgender and people with intersex traits, struggle to find culturally and clinically competent health care providers.”).

²⁸ *Id.*

²⁹ *When Health Care Isn’t Caring: Lambda Legal’s Survey on Discrimination Against LGBT People and People Living with HIV*, LAMBDA LEGAL (2010), https://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-report_when-health-care-isnt-caring.pdf.

concluded that members of the LGBT community expect to experience such discrimination which discourages many from seeking critical care, lest they suffer the above indignities.³⁰

Moreover, the Department's Healthy People 2020 initiative further confirms that "LGBT individuals face health disparities linked to societal stigma, discrimination, and denial of their civil and human rights."³¹ In a study published in Health Affairs, researchers concluded that discrimination, as well as "insensitivity or disrespect on the part of health care providers," were key barriers to health care access.³² Sixteen percent of LGBTQIA+ people reported discrimination when going to a doctor or health clinic.³³ Furthermore, eighteen percent of LGBTQIA+ people avoid seeking medical care due to discrimination they have experienced in the past or expect to experience.³⁴ In 2017, 4.5% of Americans identified as LGBTQIA+. Therefore, about eleven million people identify as LGBTQIA+ in the U.S.³⁵ These eleven million people deserve equal health care access and should not be subjected to discrimination that impacts their health.

One individual in Philadelphia avoided appointments with her primary care physician because her physician responded with "[d]o you know that's against the Bible, against God?" when the individual shared that she was a lesbian.³⁶ An eighteen-year-old in Eastern Pennsylvania underwent thousands of dollars of unnecessary medical testing because his doctors failed to ask him about his sexual orientation.³⁷ His diagnosis and treatment were delayed because his doctors relied on the presumption of heterosexuality.³⁸ This less overt discrimination is still harmful; it impeded the patient's access to appropriate health care and caused unnecessary delay, cost, and additional suffering.

These problems persist in 2022. Data in a new report from the Center for American Progress "reveal[s] that LGBTQI+ communities encounter discrimination and other challenges when interacting with health care providers and health insurers, underscoring the importance of strengthening nondiscrimination

³⁰ *Id.*

³¹ Healthy People 2020, *Lesbian, Gay, Bisexual, and Transgender Health*, Healthy People 2020 (last updated Feb. 6, 2022), <https://wayback.archive-it.org/5774/20220413203148/https://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health>.

³² Ning Hsieh & Matt Ruther, *Despite Increased Insurance Coverage, Nonwhite Sexual Minorities Still Experience Disparities in Access to Care*, 36 HEALTH AFF. 1786, 1786 (Oct. 2017), <https://www.healthaffairs.org/doi/10.1377/hlthaff.2017.0455>.

³³ Harvard Opinion Research Program, *Discrimination in America*, NPR, ROBERT WOOD JOHNSON FOUNDATION & HARVARD T.H. SCHOOL OF PUBLIC HEALTH 13 (Jan. 2018), <https://cdn1.sph.harvard.edu/wp-content/uploads/sites/94/2018/01/NPR-RWJF-HSPH-Discrimination-Final-Summary.pdf>.

³⁴ Shabab Ahmed Mirza & Caitlin Rooney, *Discrimination Prevents LGBTQ People from Accessing Healthcare*, CENTER FOR AMERICAN PROGRESS (Jan. 18, 2018), <https://www.americanprogress.org/issues/lgbt/news/2018/01/18/445130/discrimination-prevents-lgbtq-people-accessing-health-care/>.

³⁵ Frank Newport, *In U.S., Estimate of LGBT Population Rises to 4.5%*, GALLUP POLLS (May 22, 2018), https://news.gallup.com/poll/234863/estimate-lgbt-population-rises.aspx?%20g_source=link_NEWSV9&g_medium=TOPIC&g_campaign=item_&g_content=In%2520U.S.%2c%2520Estimate%2520o%20f%2520LGBT%2520Population%2520Rises%2520to%25204.5%2525.

³⁶ *When Health Care Isn't Caring: Lesbian, Gay, Bisexual and Transgender (LGBT) People and People Living with HIV Speak Out*, LAMBDA LEGAL 1 (2010), https://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-insert_lgbt-people-and-people-living-with-hiv-speak-out.pdf.

³⁷ *Id.* at 3.

³⁸ *Id.*

protections through Section 1557 of the Affordable Care Act.”³⁹ Specifically, among transgender people who visited a doctor or healthcare provider’s office in 2017, twenty-nine percent said a doctor or other healthcare provider refused to see them because of their actual or perceived gender identity, and twelve percent said a doctor or other healthcare provider refused to provide gender affirming healthcare.⁴⁰

Moreover, eighty percent of “transgender adults report being treated with less courtesy or respect than their cisgender heterosexual counterparts,” and nearly half of transgender adults reported experiences of discrimination with a health care provider.⁴¹ Consequently, transgender adults are considerably less likely to pursue preventative care and routine doctor’s visits.⁴² For example, Jesse Brace, who identifies as transgender and nonbinary, avoided pursuing medical care for years despite suffering recurring seizures that increased in frequency to hundreds of times a day.⁴³ They endured suffering physically, loss of employment, and homelessness rather than seeking medical care after multiple health care providers ignored what they shared about their being transgender, refused to use their personal pronouns, and refused to provide treatment for their recurring seizures.⁴⁴ No one should have to make a choice between personal dignity and being treated with respect and vital health care. Furthermore, no one should be turned away by health care providers based on their status as transgender or their gender identity.

Therefore, the updated definition of “on the basis of sex” included in §92.101 is critical to protecting access to health care for the LGBTQI+ community. However, given the demonstrated tendency of health care insurers, providers, and associated businesses and personnel to discriminate against LGBTQI+ people, it is critical that the definition of “on the basis of sex” in §92.101 be explicit and comprehensive.

We suggest that the provision be revised as follows:

“Discrimination on the basis of sex includes, but is not limited to, discrimination on the basis of sex stereotypes; sex characteristics, including intersex traits; pregnancy or related conditions, **including termination of pregnancy**; sexual orientation; **transgender status**; and gender identity.”

Finally, we suggest that this definition in §92.101 be used *consistently throughout* the Final Rule rather than a truncated version. Our concern is that inconsistency could cause confusion and may create an opportunity for future discrimination against a historically vulnerable population.

i. The Proposed Rule supports equal program access on the basis of sex.

We are particularly supportive of the changes to §92.206 paragraphs (b) and (c) regarding Equal Program Access on the Basis of Sex.⁴⁵ These changes require health care insurers and providers to give someone a

³⁹ Caroline Medina et al., *Advancing Health Care Nondiscrimination Protections for LGBTQI+ Communities*, CENTER FOR AMERICAN PROGRESS ACTION FUND, Figure 3, Figure 13 (Sept. 8, 2022), <https://www.americanprogress.org/article/advancing-health-care-nondiscrimination-protections-for-lgbtqi-communities/>.

⁴⁰ Mirza & Rooney, *supra* note 34.

⁴¹ Caroline Medina et al., *supra* note 39.

⁴² *Id.* at Figure 6.

⁴³ Jo Yurcaba, *Nearly Half of Trans People Have Been Mistreated by Medical Providers, Report Finds*, NBC NEWS (updated Aug. 19, 2021), <https://www.nbcnews.com/nbc-out/out-health-and-wellness/nearly-half-trans-people-mistreated-medical-providers-report-finds-rcna1695>.

⁴⁴ *Id.*

⁴⁵ 87 Fed. Reg. at 47866-69.

mammogram or pap smear if it is medically necessary regardless of the individual’s gender expression.⁴⁶ It is critical that people not have to choose between critical health care services and their gender expression, gender identity or transgender status. These updates remove significant barriers preventing LGBTQI+ people from accessing necessary health care.

ii. The Proposed Rule supports gender affirming care for transgender people.

We strongly support the inclusion of gender affirming care to §92.207.⁴⁷ The text clarifies that providers may not refuse gender affirming care based on a personal belief that such care is not 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.

Gender affirming care is necessary for the mental health and social wellbeing of transgender people.⁴⁸ “Medical experts agree: gender-affirming care is medically necessary care that can be life-saving for transgender”⁴⁹ people who suffer disproportionately from anxiety, depression, and suicidal ideation as compared to cisgender people.⁵⁰ Therefore, to strengthen protections we suggest that “transgender status” be added to §§92.206(b)(1), (b)(2) and (b)(4) of the Final Rule.

iii. Federal anti-discrimination protection for LGBTQI+ people is critical in Pennsylvania.

The Proposed Rule coupled with the above suggestions are particularly critical for the twenty-seven states that do not currently have anti-discrimination protections for LGBTQ+ people enshrined in state law, including Pennsylvania.⁵¹ While Pennsylvania does have some executive protection, it is limited in scope and transient as it depends on the current administration.⁵² The “patchwork of existing protections” in Pennsylvania is not a long-term solution, particularly of state legislators’ incessant efforts to target

⁴⁶ *Id.*

⁴⁷ 87 Fed. Reg. at 47872-72.

⁴⁸ *Outlawing Trans Youth: State Legislatures and the Battle over Gender-Affirming Healthcare for Minors*, 134 HARV. L.REV. 2163 (Apr. 12, 2021), <https://harvardlawreview.org/2021/04/outlawing-trans-youth-state-legislatures-and-the-battle-over-gender-affirming-healthcare-for-minors/>; Brief of the Am. Med. Ass’n, The Am. Coll. of Physicians & 14 Additional Med., Mental Health & Health Care Orgs. as Amici Curiae Supporting Petitioners at 4, 12, 17, 19, 22-23, *Bostock v. Clayton County*, 590 U.S. ___, 140 S. Ct. 1731 (2020) (Nos. 17-1618, 17-1623, 18-107), https://www.supremecourt.gov/DocketPDF/17/17-1618/107177/20190703172548842_Amicus%20Brief.pdf (inadequate access to gender affirming health care and social stigma have deleterious impact on mental, physical, and over-all well-being of transgender individuals).

⁴⁹ ACLU, *Doctors Agree: Gender-Affirming Care is Life-Saving Care* (Apr. 1, 2021),

<https://www.aclu.org/news/lgbtq-rights/doctors-agree-gender-affirming-care-is-life-saving-care>.

⁵⁰ Kareen M. Matouk & Melina Wald, *Gender-Affirming Care Saves Lives*, COLUM. UNIV. DEP’T OF PSYCHIATRY (Mar. 30, 2022), <https://www.columbiapsychiatry.org/news/gender-affirming-care-saves-lives>.

⁵¹ FREEDOM FOR ALL AMES., *LGBTQ Americans Aren’t Fully Protected from Discrimination in 29 States* (Sept. 19, 2022), <https://freedomforallamericans.org/states/>; Amal Bass, *Pennsylvania Needs to Codify LGBTQ+ Protections*, THE REGUL. REV. (June 23, 2021), <https://www.theregreview.org/2021/06/23/bass-pa-codify-lgbtq-protections/>.

⁵² OFFICE OF ATT’Y GEN. JOSH SHAPIRO, *LGBTQ+ Equality* (Sept. 19, 2022),

<https://www.attorneygeneral.gov/protect-yourself/civil-rights/lgbtq-equality/> (Pennsylvania Human Relations Commission and Civil Rights Enforcement Section accept and address LGBTQ+ discrimination complaints as discrimination on the basis of sex).

LGBTQI+ protections.⁵³ Therefore, strong federal protection via Section 1557 is critical for Pennsylvania and most states.

b. The Final Rule should explicitly include “termination of pregnancy” in the definition of “on the basis of sex.”

As mentioned above, the definition of “on the basis of sex” must be fully comprehensive and standardized throughout the Proposed Rule. While we support the Department’s decision to include “pregnancy or related conditions” in the Proposed Rule’s definition of “on the basis of sex,” that is far too vague given the ongoing attacks on reproductive health care access, specifically health care related to termination of pregnancy.⁵⁴

Access to reproductive health care, including termination of pregnancy, is critical. Abortion access allows people who become pregnant to exercise agency over their reproductive health, education, careers, and lifestyle.⁵⁵ It also benefits maternal health.⁵⁶ Furthermore, per data collected in 2020, pregnant people in the U.S. are more likely to die during pregnancy than in any other developed country.⁵⁷ The U.S. has a maternal morbidity rate three times that of the second-worst ranked developed country.⁵⁸ Even more disturbing is that the U.S. is “the only country with an advanced economy where the [maternal mortality rate] is getting worse.”⁵⁹ This includes preventable deaths which amount to over eighty percent of all pregnancy-related deaths in the U.S.⁶⁰ The maternal morbidity rate in Pennsylvania has doubled since 1994.⁶¹

⁵³ Bass, *supra* note 51 (LGBTQ+ antidiscrimination protections should be codified at all levels of government including at the federal level—via the Equality Act—and at state level—Pennsylvania Fairness Act in Pennsylvania—for enduring protection).

⁵⁴ See *Dobbs*, 142 S. Ct. (2022) (overturning *Roe v. Wade*, 410 U.S. 113 (1973)); David S. Cohen, Greer Donley & Rachel Rebouché, *Rethinking Strategy After Dobbs*, 75 STAN. L.REV. ONLINE 1 (2022), <https://review.law.stanford.edu/wp-content/uploads/sites/3/2022/08/Cohen-et-al.-75-Stan.-L.-Rev.-Online-1.pdf>.

⁵⁵ Sheelah Kolhatkar, *The Devastating Economic Impacts of an Abortion Ban*, THE NEW YORKER (May 11, 2022), <https://www.newyorker.com/business/currency/the-devastating-economic-impacts-of-an-abortion-ban>.

⁵⁶ Anusha Ravi, *Limiting Abortion Access Contributes to Poor Maternal Health Outcomes*, CENTER FOR AM. PROGRESS (June 13, 2018), <https://www.americanprogress.org/article/limiting-abortion-access-contributes-poor-maternal-health-outcomes/>.

⁵⁷ Virginia Langmaid, *Study of wealthy nations finds American women most likely to die of preventable causes, pregnancy complications*, CNN (Apr. 5, 2022), <https://www.cnn.com/2022/04/05/health/us-women-health-care/index.html>.

⁵⁸ *Id.*

⁵⁹ Pilar Herrero et al., *Black Mamas Matter: Advancing the Human Right to Safe and Respectful Maternal Health Care*, BLACK MAMAS MATTER ALL. 9 (2018), https://www.reproductiverights.org/sites/default/files/documents/USPA_BMMA_Toolkit_Booklet-Final-Update_Web-Pages.pdf.

⁶⁰ Langmaid, *supra* note 57; CDC Newsroom, *Four in 5 Pregnancy-Related Deaths in the U.S. are Preventable* (Sept. 19, 2022), <https://www.cdc.gov/media/releases/2022/p0919-pregnancy-related-deaths.html>.

⁶¹ Governor Tom Wolf, *Governor Wolf Signs Bill to Investigate Maternal Deaths* (May 9, 2018), <https://www.governor.pa.gov/newsroom/governor-wolf-signs-bill-investigate-maternal-deaths/>.

Often, discrimination based on termination of pregnancy is rooted in abortion stigma.⁶² A majority of people seeking abortion experience this type of discrimination.⁶³ This stigma is rooted in sex-based conventions that paint women as: inherently nurturing and maternal; chaste (an assumption shattered by an unwanted pregnancy); and desiring to give birth and fulfill traditional roles of homemaker and child caretaker.⁶⁴ These sex-based conventions, however, are simply sex stereotypes upon which discrimination in health care access and quality is expressly prohibited.⁶⁵ The stigmatization of abortion also stems from a universal misperception that abortion is an immoral act as opposed to a personal medical decision.⁶⁶

Abortion stigma often shapes the experiences of patients seeking all forms of medical care, simply because they present as capable of pregnancy.⁶⁷ Sex-based discrimination in health care—including abortion care—has a disproportionate impact on women and transgender and non-binary individuals in comparison to cis men.⁶⁸ When reproductive health care is marred by abortion stigma, the stigma “diminishes the trust that is essential to the patient-provider relationship and undermines women’s ability to make informed medical decisions.”⁶⁹ These experiences are precisely the discriminatory conduct that Section 1557 protects against.

Therefore, we suggest that the provision in §92.101 be revised as follows:

“Discrimination on the basis of sex includes, but is not limited to, discrimination on the basis of sex stereotypes; sex characteristics, including intersex traits; pregnancy or related conditions, **including termination of pregnancy**; sexual orientation; **transgender status**; and gender identity.”

Additionally, we suggest that this definition in §92.101 be used *consistently throughout* the Final Rule rather than a truncated alternative. Our concern, again, is that inconsistency could cause confusion and may create an opportunity for future discrimination against a historically vulnerable population.

This consistency and clarification are critical because people needing health care regarding termination of pregnancy can be discriminated against in a myriad of ways. For example, patients needing emergency abortion care have been denied care at hospitals. Patients have reported being denied medical care unrelated to abortion because their medical history includes a prior abortion. Pharmacies have refused to

⁶² Alison Norris et al., *Abortion Stigma: A Reconceptualization of Constituents, Causes, and Consequences*, 21 WOMEN’S HEALTH ISSUES 1, 6 (2011), <https://www.guttmacher.org/sites/default/files/pdfs/pubs/journals/Abortion-Stigma.pdf>; Anuradha Kumar et al., *Conceptualizing Abortion Stigma*, 11 CULTURE, HEALTH & SEXUALITY 625, 628-29 (2009).

⁶³ See Paula Abrams, *The Scarlet Letter: The Supreme Court and the Language of Abortion Stigma*, 19 MICH. J. GENDER & L. 293, 328-29 (2013); M. ANTONIA BIGG ET AL., PERCEIVED ABORTION STIGMA & PSYCH. WELL-BEING OVER FIVE YEARS AFTER RECEIVING OR BEING DENIED AN ABORTION 2 (Whitney S. Rice ed., 2020) (finding that most people considering abortion perceive some stigma related to their decision).

⁶⁴ Norris, *supra* note 62, at 6; Kumar, *supra* note 62, at 628-29.

⁶⁵ 87 Fed. Reg. at 47858.

⁶⁶ COCKRILL K. ET AL., ADDRESSING ABORTION STIGMA THROUGH SERVICE DELIVERY: A WHITE PAPER 17 (2013).

⁶⁷ Transgender, nonbinary, and gender-expansive people who were assigned female or intersex at birth experience pregnancy, have abortions, and are underrepresented and underserved in abortion policy discourse. See e.g. Heidi Moseson et al., *Abortion Experiences and Preferences of Transgender, Nonbinary, and Gender-expansive People in the United States*, 224 AM. J. OBSTETRICS & GYNECOLOGY 1, 1-2 (Sept. 2020).

⁶⁸ See Emily Paulsen, *Recognizing, Addressing Unintended Gender Bias in Patient Care*, DUKE HEALTH (Jan. 14, 2020), <https://physicians.dukehealth.org/articles/recognizing-addressing-unintended-gender-bias-patient-care>.

⁶⁹ NAT’L P’SHIP FOR WOMEN & FAMS., BAD MEDICINE: HOW POLITICAL AGENDA IS UNDERMINING ABORTION CARE AND ACCESS 2 (2019), <https://www.nationalpartnership.org/our-work/repro/reports/bad-medicine-oklahoma.html>.

fill prescriptions needed to manage a miscarriage or complications from pregnancy loss because these medications can also be used to terminate a pregnancy.

Patients need to know that they cannot be discriminated against based on termination of pregnancy, and we urge the Department to make this clear in its Final Rule. This is particularly urgent considering the public health crisis unfolding across the country as many communities no longer have access to legal abortion care. Accordingly, the Department should explicitly identify “termination of pregnancy” in any text where “pregnancy or related conditions” is defined as part of sex discrimination.

i. The Final Rule must explicitly enumerate the full ambit of reproductive health care.

Section 1557’s protection against sex discrimination includes protections against discrimination relating to all reproductive health decisions. Unfortunately, this is not seen in practice. For instance, when seeking a hysterectomy or excisions to help remedy chronic pain caused by endometriosis, patients have been refused care by doctors who believe the patient is making the wrong choice and will one day want to have children.⁷⁰ This is an inappropriate limitation on an individual’s agency in making health care decisions based on a health care provider’s personal—and non-medical—opinion.

The Final Rule must explicitly highlight that the ambit of Section 1557’s anti-discrimination reach includes fertility care, contraception, mistreatment in maternity care, and sex discrimination in access to medications and treatments for disabilities and emergency medical conditions.

ii. The Final Rule should explicitly state that it prohibits all forms of discrimination related to reproductive health care.

In this post-*Dobbs* world, any person capable of pregnancy or who presents as such may be subject to discrimination while seeking health care. Patients seeking life-threatening emergency care for pregnancy or related conditions may be turned away by providers refusing to provide care. Additionally, patients may not be given information or referrals regarding abortion or other reproductive health care options that they should be informed of. Health care access and quality may also be impacted by the intersection of maternity and race.⁷¹ Furthermore, patients who have had an abortion in the past may be denied care for unrelated medical conditions because their provider is anti-abortion.

One in four women in the United States will have an abortion by the age of forty-five, and many more will inquire about abortion.⁷² Therefore, at least a quarter of women are vulnerable to discrimination based on their personal choice. This is further exacerbated when considering the intersectionality with race and socio-economic level because nearly two-thirds of abortions are obtained by people of color⁷³

⁷⁰ Anne Branigin, *Choosing Between not Having Kids or Pain: An Endometriosis Case is Sparking Outrage*, THE LILY (Apr. 20, 2021), <https://www.thelily.com/choosing-between-children-and-a-lifetime-of-pain-a-endometriosis-case-in-the-uk-is-sparking-outrage/>.

⁷¹ Saraswathi Vedam et al., *The Giving Voice to Mothers Study: Inequity and Mistreatment During Pregnancy and Childbirth in the United States*, 16 REPROD. HEALTH 1 (2019), <https://doi.org/10.1186/s12978-019-0729-2> (finding pregnant Black, Indigenous, Latina/x, Asian American and Pacific Islander, and all people of color, and others who live at the intersections of Section 1557’s protected identities, often suffer discrimination throughout pregnancy and postpartum period, including mistreatment during labor and delivery).

⁷² GUTTMACHER INSTITUTE, *United States: Abortion* (2022), <https://www.guttmacher.org/united-states/abortion>.

⁷³ Jenna Jerman et al., *Characteristics of U.S. Abortion Patients in 2014 and Changes Since 2008*, GUTTMACHER INSTITUTE (May 2016), <https://www.guttmacher.org/report/characteristics-us-abortion-patients-2014>.

and nearly half of abortions patients were living below the federal poverty level in 2014.⁷⁴ In Pennsylvania specifically, 32,123 abortions were performed in 2020 and over half were to people of color.⁷⁵

It is imperative that this significant population has unencumbered health care access and quality, and that they are not forced to choose between being treated poorly and accessing vital health care. Therefore, the Department must explicitly state that it prohibits all forms of discrimination related to reproductive health care.

III. LANGUAGE ASSISTANCE IS ESSENTIAL FOR ENSURING INDIVIDUALS WITH LIMITED ENGLISH PROFICIENCY TO HAVE MEANINGFUL AND EQUITABLE ACCESS TO HEALTH CARE.

a. Notice of language assistance services and notice of rights and accommodations

WLP strongly supports the Proposed Rule's changes to strengthen discriminatory protections for people with limited English proficiency ("LEP"), including the requirements related to language assistance services and notice of nondiscrimination and accommodations.

As many as one in ten⁷⁶ working adults in the United States have LEP, and most LEP individuals are immigrants. The immigrant population is one of the most affected in terms of poverty and health disparities.⁷⁷ Immigrants with low health literacy and limited English proficiency are known to have poorer health outcomes.⁷⁸ In Pennsylvania, one in fourteen residents of the state is an immigrant.⁷⁹

Language-related barriers may severely limit an individual's opportunity to access health care, assess options, express choices, ask questions or seek assistance. This was the case for one Latinx immigrant in Pennsylvania whose ability to make reproductive health choices was severely limited because her doctor did not speak Spanish. When she inquired a medical provider about her options to have a baby while diagnosed with rheumatoid arthritis, she was simply told that adoption was her best option.⁸⁰ Her frustrating experience is not uncommon amongst individuals with LEP when encountering the health care system. Some Latinx patients have even experienced physicians refusing to treat them because they did not bring their own interpreter.⁸¹ In these unfortunate situations, monolingual Spanish speakers are forced to forgo care or left with the burden of finding a Spanish-speaking provider at an additional cost.⁸² This is

⁷⁴ *Id.*

⁷⁵ PENNSYLVANIA DEPARTMENT OF HEALTH, *2020 Abortion Statistics* 1-3 (Dec. 2021), https://www.health.pa.gov/topics/HealthStatistics/VitalStatistics/Documents/Pennsylvania_Annual_Abortion_Report_2020.pdf.

⁷⁶ Sheila Mulrooney Eldard, *With Scarce Access to Interpreters, Immigrants Struggle to Understand Doctors' Orders*, NPR (Aug. 15, 2018), <https://www.npr.org/sections/health-shots/2018/08/15/638913165/with-scarce-access-to-medical-interpreters-immigrant-patients-struggle-to-understands>.

⁷⁷ Cindy Chang, *Social Determinants of Health and Health Disparities Among Immigrants and Their Children*, 49 ADOLESCENT HEALTH CARE 23-30, 23 (2019).

⁷⁸ Tetine Sentell et al., *Low Health Literacy, Limited English Proficiency, and Health Status in Asians, Latinos, and Other Racial/Ethnic Groups in California*, 17 J. HEALTH COMM. 82, 92 (2012).

⁷⁹ Am. Immigr. Council, *Immigrants in Pennsylvania*,

<https://www.americanimmigrationcouncil.org/research/immigrants-in-pennsylvania> (last visited Sep. 28, 2022).

⁸⁰ Pa. Campaign for Women's Health, *A Report on Pennsylvania's Community Conversations on Women's Health* 24 (Jan. 2018), https://www.womenslawproject.org/wp-content/uploads/2022/09/PA4WomensHealth_Community-Conversations_Final-Report.pdf.

⁸¹ *Id.* at 25.

⁸² *Id.*

especially concerning because Latinas often experience financial insecurity and pay discrimination in the workforce. In Pennsylvania, Latinas working full-time earn only fifty-seven cents on the dollar for every dollar a white, non-Hispanic male makes, on average.⁸³ Language proficiency should not determine the quality of an individual's access to comprehensive health care services and should not be a barrier to receiving accurate and complete information that centers the needs of the individual patient and their health goals.

Critically, the Proposed Rule restores a number of the provisions stripped by the Trump administration in the 2020 Rule, including a requirement to take reasonable steps to provide meaningful access to each LEP individual.⁸⁴ The Proposed Rule also reinstates requirements to notify LEP individuals of the availability of language services. The 2016 Rule included requirements for taglines on significant documents.⁸⁵ The Proposed Rule reinstated notification requirements albeit with a new name and some changed parameters. First, the name is now "notice of availability of language assistance services and auxiliary aids and services" to cover notice to both LEP individuals and people with disabilities.⁸⁶ The notice must be provided in English and the top fifteen languages in the state.⁸⁷ The notice must be provided annually, upon request, at a conspicuous location on the entity's website, and in a clear and prominent physical location.⁸⁸ The Proposed Rule offers an "opt-out" provision if individuals want to opt out of receiving this notice.⁸⁹

These changes are an important advancement for providing health care to individuals with LEP, but the significant shortage of bilingual and medical interpreters in the healthcare system poses a major problem that must be addressed.⁹⁰ Language-related barriers increase the risk of miscommunication and patient safety. For example, in 2018, NPR reported a related account from the director of language services at Children's Hospital of Philadelphia ("CHOP") who recalled one young mother-to-be with a high-risk pregnancy referred to them by another clinic.⁹¹ The referring clinic had allowed the woman's sister-in-law to act as her interpreter. While the providers at the clinic told the sister-in-law the woman's fetus was at risk of heart damage, the message was never relayed to the woman. When CHOP delivered the news, the woman was in utter despair. She had enjoyed her baby shower and even prepped a nursery.

Language access is one of several barriers to equity in telehealth faced by communities of color, particularly in delivery of reproductive health care services.⁹² Women of color are disproportionately represented among abortion patients.⁹³ Black, Latinx, and low-income individuals seek abortions in

⁸³ *Id.* at 22.

⁸⁴ 87 Fed. Reg. at 47860-64.

⁸⁵ 87 Fed. Reg. at 47852.

⁸⁶ 87 Fed. Reg. at 47853.

⁸⁷ 87 Fed. Reg. at 47852.

⁸⁸ 87 Fed. Reg. at 47901.

⁸⁹ *Id.*

⁹⁰ Ronnie Cohen, *Required Translators Missing from Many U.S. Hospitals*, REUTERS (Aug. 11, 2016), <https://www.reuters.com/article/us-health-translators/required-translators-missing-from-many-u-s-hospitals-idUSKCN10M29M>.

⁹¹ Sheila Mulrooney Eldard, *With Scarce Access to Interpreters, Immigrants Struggle to Understand Doctors' Orders*, NPR (Aug. 15, 2018), <https://www.npr.org/sections/health-shots/2018/08/15/638913165/with-scarce-access-to-medical-interpreters-immigrant-patients-struggle-to-under>.

⁹² Terri-Ann Thompson et al., *Addressing Structural Inequities, a Necessary Step Toward Ensuring Equitable Access to Telehealth for Medication Abortion Care During and Post COVID-19*, 3 FRONTIERS GLOB. WOMEN'S HEALTH 1, 4 (2022).

⁹³ DAVID S. COHEN & CAROLE JOFFE, *OBSTACLE COURSE: THE EVERYDAY STRUGGLE TO GET AN ABORTION IN AMERICA* 13 (2020).

higher rates compared to their white counterparts⁹⁴ due in part to higher rates of unintended pregnancy, a consequence of systemic inequities to access to health care such as access to contraceptives.⁹⁵ These populations experience reduced access to abortion services.⁹⁶ While telehealth has the potential to address barriers to abortion care and expand access, neighborhoods populated predominately by people of color lack access to the internet and other technology resources compared to wealthier, white neighborhoods.⁹⁷ The result is reduced abilities for Black and Latinx communities to meaningfully access health care services via telehealth. Further, initial studies during the COVID-19 pandemic demonstrate varying levels of acceptance of telehealth, with Black respondents favoring telehealth visits over Spanish-speaking Latinx respondents due to unaddressed language access issues.⁹⁸ Intersectionality is an important consideration when addressing the needs of individuals with LEP.

Even filing a complaint with the Department also requires communication skills or related assistance. The Department received 210 language-access complaints during the five-year span ending in 2017.⁹⁹ In Pennsylvania, only 232 events associated with language barriers and LEP were reported to the Pennsylvania Patient Safety Authority from June 2004 through May 2010.¹⁰⁰ We strongly encourage the Department to consider its current practices to its ensure grievance procedures are actually accessible to individuals with LEP.

Unfortunately, there is no dedicated funding available to covered entities to take reasonable steps to provide meaningful access to individuals with LEP. States are not required to reimburse providers for the cost of language services despite the option to do so under Medicaid and CHIP. Given that language access benefits bottom lines by saving hospitals costs¹⁰¹ from readmissions due to poor interpretation services, the Department should also consider ways to incentivize covered entities to provide language assistance services.

b. WLP supports the Department’s non-discriminatory prohibitions in the use of clinical algorithms and cautiously recommends data collection for the purposes of research.

Algorithms and other types of automated decision-making systems (“ADS”) play an important role in health care eligibility and coverage determinations. However, such systems may make discriminatory determinations due to bias and imperfect data. When assessment tools using ADS are used with LEP patients, additional errors may occur, particularly if qualified interpreters are not utilized to ensure the information needed in the tools is accurate and comprehensive. The Proposed Rule explains that

⁹⁴ Rachel K. Jones et al., *Population Group Abortion Rates and Lifetime Incidence of Abortion: United States, 2008–2014*, 107 AM. J. PUB. HEALTH 1284, 1288 (2017).

⁹⁵ Michele Troutman et al., *Are Higher Unintended Pregnancy Rates Among Minorities a Result of Disparate Access to Contraception?*, 5 CONTRACEPTION & REPROD. MED. 1, 2 (2020).

⁹⁶ Heather Boonstra, *Abortion in the Lives of Women Struggling Financially: Why Insurance Coverage Matters. Available*, GUTTMACHER POL’Y REV. (July 14, 2016), <https://www.guttmacher.org/gpr/2016/07/abortion-lives-women-struggling-financially-why-insurance-coverage-matters>.

⁹⁷ Shara Tibken, *The Broadband Gap’s Dirty Secret: Redlining Still Exists in Digital*, CNET (28 June 2021), <https://www.cnet.com/features/the-broadband-gaps-dirty-secret-redlining-still-exists-in-digital-form/>.

⁹⁸ California Pan-Ethnic Health Network, *Equity in the Age of Telehealth: Considerations for California Policymakers* 6-11 (Dec. 4, 2020), <https://cpehn.org/assets/uploads/2020/12/telehealthfactsheet-12420-d-1.pdf>.

⁹⁹ Eldard, *supra* note 76.

¹⁰⁰ Patient Safety Authority, *Managing Patients with Limited English Proficiency*, http://patientsafety.pa.gov/ADVISORIES/Pages/201103_26.aspx (last visited Aug. 28, 2022).

¹⁰¹ Leah S. Karliner, *Convenient Access to Professional Interpreters in the Hospital Decreases Readmission Rates and Estimated Hospital Expenditures for Patients with Limited English Proficiency*, 55 MED. CARE 199, 199 (2017).

discrimination through the use of algorithms is already unlawful under Section 1557.¹⁰² And it introduces a stand-alone regulation expressly prohibiting discrimination through decisions based on clinical algorithms.¹⁰³ The new provision puts covered entities on notice that while they are not liable for discrimination in algorithms they use, they will be held accountable for discriminatory decisions they make based on such clinical algorithms.

While the preamble to the Proposed Rule discusses the Department's intended use of existing civil rights authority to develop a system for requesting compliance data from covered entities, the Department should establish a specific provision within the proposed rule that will require covered entities that use electronic health records to systematically collect and maintain demographic information including but not limited to race, ethnicity, language, sex, gender, gender identity, sexual orientation, disability and age data in a manner that adheres to patient privacy concerns and applicable state and federal laws. Improved and tailored sampling methodologies are required to thoroughly explore research questions on the health and well-being of intersectional sub-population groups. As such, intentional and good-faith data collection is paramount to protect people's privacy, ensure reliable data analyses, and avoid discriminatory algorithmic determinations.

IV. THE DEPARTMENT SHOULD REVISE THE PROPOSED RULE TO INCLUDE EXPLICIT PROTECTIONS AGAINST INTERSECTIONAL DISCRIMINATION.

We strongly support the Department's inclusion of intersectionality in the preamble and its consideration of the impact of intersectional discrimination on health care access and quality.¹⁰⁴ Intersectionality, as introduced by civil rights advocate and critical race theory scholar Kimberlé Crenshaw,¹⁰⁵ acknowledges that an experience of discrimination can occur "at the intersection of multiple forms of oppression" where the impacted individual exists.¹⁰⁶ Intersectional discrimination is discrimination that occurs multidimensionally where each dimension or axis represents a different facet of the impacted individual's identity.¹⁰⁷

Indeed, an intersectional analysis can afford meaningful protection for individuals who experience health care discrimination originating from any permutation of sexism (including people who are pregnant, people who are perceived as being capable of pregnancy, or LGBTQI+ people), racism, xenophobia (e.g., people with LEP), ableism, or ageism. Similarly, people with low-incomes and or who live below the poverty level suffer diminished health care options.

For example, even though "most pregnancy related deaths are preventable[,] . . . Black women are three times more likely to die from a pregnancy-related cause than [w]hite women."¹⁰⁸ In Pennsylvania

¹⁰² 87 Fed. Reg. at 47880.

¹⁰³ *Id.*

¹⁰⁴ 87 Fed. Reg. at 47837, 47870.

¹⁰⁵ Kimberlé Crenshaw on Intersectionality, *More than Two Decades Later*, NEWS FROM COLUM. L. SCH. (June 8, 2017), <https://www.law.columbia.edu/news/archive/kimberle-crenshaw-intersectionality-more-two-decades-later>.

¹⁰⁶ Jill E. Adams & Jessica Arons, *A Travesty of Justice: Revisiting Harris v. Mcrae*, 21 WM. & MARY J. WOMEN & L. 5, 51 (2014).

¹⁰⁷ See Kimberlé Crenshaw, *Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics*, 1989 UNIV. OF CHI. LEGAL F. 139, 139-40, 166-67 (1989) (intersectionality used to fully characterize the experience of Black women).

¹⁰⁸ CTR. FOR DISEASE CONTROL, *Working Together to Reduce Black Maternal Mortality* (Apr. 6, 2022), <https://www.cdc.gov/healthequity/features/maternal-mortality/index.html>.

specifically, the 2021 maternal mortality rate of Black women is twice that of white women.¹⁰⁹ This is even more shocking when considering that Black people are 12.4% of the Pennsylvania population in 2020¹¹⁰ but suffer forty-eight percent of all pregnancy-associated deaths in 2021.¹¹¹

Therefore, at the intersection of sex—people who are pregnant—and race—Black women—there is an acute discrepancy in mortality rate.¹¹² This has been attributed to the quality of health care, structural racism, and implicit bias that prevents black people who are pregnant from getting sufficient care as compared to white people in the same situation.¹¹³ Therefore, the confluence of discrimination on the basis of sex and race significantly impacts an individual’s access to and quality of health care.¹¹⁴ The impact of intersectional discrimination is further exacerbated to the patient’s detriment if the patient is faced with compounded discrimination based on having low-income, LEP status, or a disability.

However, acknowledging the concept of intersectionality and associated dangers alone, without including explicit protections in the Proposed Rule, stops short of affording meaningful protection and relief to individuals who experience intersectional discrimination. For genuine, impactful protection against discrimination for vulnerable individuals, intersectionality protections and enforcement must be included in the regulatory text. We suggest amending the proposed language in §92.101(a)(1) to highlight that intersectional discrimination is expressly prohibited:

“Except as prohibited in Title I of the ACA, an individual must not, on the basis of race, color, national origin, sex, age, disability, **or any combination thereof**, be excluded from participation in, be denied the benefits of, or otherwise be subjected to discrimination under any health program or activity operated by a covered entity.”

The suggested language should be used consistently through the document. In particular, “or any combination thereof” should be added to §§ 92.207(a), (b)(1), and (b)(2).

Finally, we are concerned that intersectionality is not properly considered in the reporting and enforcement procedures. There is a harmful contradiction in the preamble’s acknowledgement of intersectionality and the enforcement mechanism, detailed in §92.301. While the preamble of the Proposed Rule acknowledges intersectionality, the enforcement mechanisms contradict this by requiring individuals to utilize the reporting structures under “[T]itle VI, [T]itle IX, [S]ection 794, or such Age Discrimination Act.”¹¹⁵ Therefore, an individual experiencing intersectional discrimination must report the discrimination discretely which undercuts the gravity and impact of their experiences and likely impacts any corrective actions taken against the perpetrators.

Therefore, the Department must introduce a clear and accessible procedure for individuals to report discrimination and for the agency to investigate and remediate complaints, including instances of

¹⁰⁹ BUREAU OF FAM. HEALTH, *Pennsylvania Maternal Mortality Review: 2021 Report*, PA. DEP’T OF HEALTH 8-9 (Jan. 2022),

<https://www.health.pa.gov/topics/Documents/Programs/2021%20MMRC%20Legislative%20Report.pdf>.

¹¹⁰ *Pennsylvania Population Hit 13 Million in 2020*, U.S. CENSUS BUREAU (Aug. 25, 2021),

<https://www.census.gov/library/stories/state-by-state/pennsylvania-population-change-between-census-decade.html>.

¹¹¹ BUREAU OF FAM. HEALTH, *supra* note 109.

¹¹² Mashayla Hays, *Let’s Make Black Women’s Maternal Mortality a Priority in PA*, PHILA. INQUIRER, (Dec. 20, 2018), <https://www.inquirer.com/opinion/commentary/black-women-maternal-mortality-philadelphia-pennsylvania-20181220.html>.

¹¹³ CTR. FOR DISEASE CONTROL, *supra* note 108; Hays, *supra* note 112.

¹¹⁴ Hays, *supra* note 112.

¹¹⁵ 42 U.S.C. § 18116.

intersectional discrimination. We recommend that the Department create a health-specific, anti-discrimination cause of action that is subject to a single standard. This system should address any plaintiff's protected class or combination of protected classes. Without this update, individuals who experience intersectional discrimination will likely be left with less impactful remedies and insufficient protection.

V. WHILE THE PROPOSED RULE TAKES SIGNIFICANT STEPS TOWARD PROHIBITING HEALTH CARE DISCRIMINATION, FURTHER AMENDMENTS ARE REQUIRED TO ENSURE ALL INDIVIDUALS HAVE EQUITABLE ACCESS TO HEALTH CARE.

The Proposed Rule is a significant step toward providing vulnerable communities with protection against discrimination and a genuine opportunity to access vital health care. The updates are particularly significant for people who may become pregnant, LGBTQI+ people, people of color, people with LEP, people living with disabilities, and people who are vulnerable to amplified discrimination because of intersectionality. Additionally, the updates and reversals are in line with the original purpose and plain language of Section 1557 and the Affordable Care Act broadly.

The proposed changes reflect WLP's values and mission to protect and advance the health and safety of women, girls, LGBTQ people, people of color, people with LEP, people living with disabilities, and their families. However, there are several instances where the proposed changes are not comprehensive enough to achieve the intended change and provide the necessary protections. In those instances, we urge the Department to consider and implement the suggested wording we have provided.

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